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Launch of the Paediatric Early Warning Score must be matched by workforce investment

There have been some significant and positive changes in adult patient safety recently, with the National Early Warning Score (NEWS) being introduced and widely adopted in 2012 and its second iteration, NEWS2, in 2017. But, when children and young people can deteriorate significantly and quickly, why has it taken more than ten years to prioritise children in the healthcare system?

By Carli Whittaker
consultant editor, Nursing Children and Young People

The long-awaited Paediatric Early Warning Score (PEWS) has now been launched – though not mandated – as part of the System-wide Paediatric Observations Tracking (SPOT) programme by NHS England, in collaboration with the RCN and the Royal College of Paediatrics and Child Health. Initially it is for use in acute hospitals.

Attempts to standardise the approach to identifying and escalating the deteriorating child are well evidenced, but there is significant work and education to be undertaken, and investment required, to identify deteriorating children in community or out-of-hospital settings.

The ambition of SPOT to ensure that guidance about Martha's rule, which will give patients and their families in England the right to a second opinion, needs to be explored and investment for it to be used in paediatrics. Parents' and carers' intuitions about a sick child must not be undervalued but any requested review should be undertaken by the correct person.

With the NHS Long Term Workforce Plan failing to mention any uplift or investment in children's nursing nationally, who is going to be caring for our children and young people of the future? These fantastic patient safety initiatives require a children's nursing workforce if they are to be implemented.

Further information

NHS England (2023) National Paediatric Early Warning Score (PEWS) **england.nhs.uk/get-involved/cyp/pews/**

RCN: System-wide Paediatric Observations Tracking (SPOT) Programme **tinyurl.com/RCN-SPOT**

'Parents' and carers' intuitions about a sick child must not be undervalued'

Our mission
Nursing Children and Young People aims to promote excellence in neonatal, infant, children's and young people's nursing practice.

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Letby inquiry to study culture from 'ward to boardroom'

Lady Justice Thirlwall has asked all NHS neonatal nurses and managers to complete an anonymous survey

By Alison Stacey

The senior judge leading the inquiry into the crimes of Lucy Letby (pictured, right) has said she is committed to investigating issues 'from the ward to the boardroom' insisting 'NHS culture must change now'.

Announcing the inquiry's programme of work on 22 November, Lady Justice Thirlwall (pictured, left) urged all nurses and managers working in NHS neonatal units across England to complete an anonymous survey on NHS culture to aid the inquiry.

The Court of Appeal judge is tasked with examining events at the Countess of Chester Hospital leading up to the murders and attempted murders that Letby carried out while employed as a neonatal nurse and how she was able to repeatedly kill and harm babies.

The inquiry will also consider the experience of babies and their parents named in the indictment, the conduct of clinical and non-clinical staff and the structures of raising concerns, and the effectiveness of governance and external regulation including by the Nursing and Midwifery Council.

Speaking in her first public address since the inquiry was launched, Lady Thirlwall said: 'What happened to these babies and their families is indescribable. I know that many professionals – clinical and otherwise – are already implementing changes identified as necessary before this inquiry began. I expect to learn whether these changes are effective in preventing harm.'

She also set out a timeline ahead of the inquiry's first public hearings, which are planned for this autumn and will take place in Chester.

As well as the survey for neonatal nurses, a separate questionnaire has been sent to every hospital in England that has a neonatal unit. This is to be completed by the medical director and a senior non-clinical manager at each hospital. Expert witnesses will also be called to give evidence, details of which will be shared in due course.

CHILD IMMUNISATION

Nurses may take lead in immunisation programme

Nurses are likely to be at the forefront of delivering a new chickenpox immunisation programme after scientists recommended the NHS introduce the vaccine for young children.

The Joint Committee on Vaccination and Immunisation (JCVI), which advises UK health departments, said the vaccine should be given to children in two doses, at 12 months and 18 months.

Data from other countries suggest the jab – also known as the varicella vaccine – will prevent most severe cases of chickenpox, which can cause serious illness and even death.

Combined jab

The JCVI recommended the chickenpox vaccine is given as part of a combined MMRV (measles, mumps, rubella and varicella) vaccine. It also recommended a temporary catch-up programme for older children who missed out on natural immunity from catching the disease due to restrictions on socialising during the pandemic.

Independent nurse consultant, immunisation specialist nurse and Queen's Nurse Helen Donovan welcomed the recommendations.

'It's great news. It's something that has been on the cards for some time.

'My slight concern is that practice nurses may be inundated with requests from parents who want something we can't do at the moment,' she added.

Ms Donovan explained that nurses already handled enquiries about the chickenpox vaccine because it was available in other countries including Germany, Canada, Australia and the United States.

RCN NURSING AWARDS 2023

This year's winners in the Child Health award category

Recipients of the prestigious RCN Nursing Awards 2023 were revealed at a ceremony at Liverpool Cathedral on 10 November. The awards attracted the highest-ever number of entries, and the judges commended the finalists for their commitment and compassion.

The winner in the Child Health category was ISupport, of Edge Hill University, Lancashire. ISupport works with children, parents and healthcare professionals to ensure a child's emotional and psychological well-being is central to decisions about care and procedures.

The team (pictured) represents a collaboration of 50 multidisciplinary professionals from 16 countries, inspired by Katie Dixon (pictured top, second from left), who experienced multiple traumatic procedures as a child and has since been diagnosed with post-traumatic stress disorder.

ISupport has developed a set of standards that outline what good procedural practice looks like, designed to minimise anxiety and stress experienced by children when undergoing procedures. Team lead, children's nurse Lucy Bray (pictured top left), along with her colleagues, set up the ISupport website from which the standards can be downloaded by health and care professionals.

'We are proud that this work is being recognised, it is an amazing way to say thank you to all the children, young people and parents who have been part of the project,' she said. 'The team are passionate about changing practice and this award helps showcase the difference that nurses can make.'

NURSES' UNIFORMS

Blue is the colour for nurses in standardised national uniform

The colour scheme for a national uniform for nurses in England has been revealed, with blue the chosen colour for nurses and nursing associates.

The national uniform aims to standardise workwear in the health service to make it easier to distinguish between members of different healthcare teams in the NHS. It also aims to make it easier for patients to understand different NHS roles and responsibilities.

Nurses in Scotland, Wales and Northern Ireland have been wearing standardised uniforms for several years, but employers in England have retained local discretion, resulting in diverse colour coding, styles, textiles and branding.

To address this, NHS Supply Chain (NHSSC), the procurement arm of the health service, set about introducing a national uniform in England. After engagement with NHS staff and stakeholders it has revealed the colours chosen for each uniform. It is expected that a two-piece 'smart scrub tunic' will be the final design after initial consultations.

The national uniform extends to midwives, pharmacists and allied health professionals. Each profession has a colour unique to them.

Following a workforce consultation in 2021, 88% of more than 28,000 nursing respondents favoured a national uniform. About half of respondents preferred a 'smart scrub' two-piece uniform, where the tunic is more fitted than the standard scrub top and has added pockets.

NHSSC selected a supplier to make the garments this month and expects the uniform to be available in the NHS by the summer.

What the new Paediatric Early Warning Score means for nurses

The paediatric early warning system provides a standardised nursing approach for responding to seriously unwell children

By Erin Dean
health journalist

The long-awaited national Paediatric Early Warning Score (PEWS) to pick up deterioration in children has been published by NHS England and will now be rolled out to hospitals across the country.

Developed with input from clinical teams across England, the new charts provide a single system that echoes the well-established National Early Warning Score 2 used in adults.

Children's nurses have welcomed it for bringing much-needed standardisation to the approach for recognising and responding to children becoming seriously unwell.

'In the past children have needlessly and tragically died,' says RCN head of nursing practice Wendy Preston. 'Nursing is a safety-critical profession, and we have been calling for a standardised warning system in the NHS to try and stop such tragic cases from ever happening again.'

Many hospitals have developed their own forms of early warning systems for children over the years, but they will be replaced by this new version developed with the RCN and the Royal College of Paediatrics and Child Health (RCPCH).

Triggering a review

The chart, which is available on paper and digitally, comes in four age categories covering 0-11 months, 1-4 years, 5-12 years, and those aged 13 and over, and is intended for use on children's general inpatient wards.

It allocates points to the observations recorded for heart rate, respiratory rate, extent of respiratory distress, blood pressure, oxygen saturations, oxygen delivery and capillary refill time. The points lead to an overall score that triggers different levels of escalation, the routes of which are set out on the chart.

Importantly, there are other concerns that can trigger a review, regardless of the PEWS.

Parental worry about a child's health is given significant prominence. The first question on the chart involves asking the parent or carer: 'How is your child different since I last saw them?'

Nursing concern, which the form calls 'clinical intuition', and changes to a child's consciousness level can prompt a more senior review, regardless of a patient's score.

Giving parents a voice on the chart is an aspect welcomed by children's nurses, says Nathan Askew, chief nurse at Alder Hey Children's NHS Foundation Trust in Liverpool and chair of the Association of Chief Children's Nurses.

'It's a very valuable addition,' Mr Askew says. 'We always say in paediatrics the parent knows their child best and it captures that ethos. Even if the child isn't concerning from an observations point of view, if the parents have concerns then it gives them a much stronger voice in that partnership with healthcare staff.'

He says another important benefit to standardisation comes when nurses move between organisations.

'It gives us a common currency across the whole of the NHS, so everyone will know what it means for every child,' he says. 'Once people

PEWS will be aligned with any future guidance from Martha's rule

The release of t he national Paediatric Early Warning Score (PEWS), which has been years in the making, comes at a time of focus on the concerns of relatives not being listened to by healthcare staff.

It follows the case of Martha Mills, who died from sepsis days before her 14th birthday after her parents' concerns about her deterioration were not listened to by healthcare staff at King's College Hospital in London.

A coroner ruled that she would probably have survived if doctors had transferred her to intensive care earlier.

Her family have been campaigning for the introduction of Martha's rule, which will give patients or their families the right to trigger a rapid clinical review in certain circumstances. The proposed change has received government backing.

When PEWS was launched in November, health minister Maria Caulfield said the system would be aligned with any future guidance from Martha's rule.


BBC

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Parental concern about a child's health is given prominence in paediatric early warning systems

have been trained when they move organisations or they're doing a shift somewhere else, again it's the same language, the same currency. That's the biggest benefit.'

Association of British Paediatric Nurses chair Caron Eyre says the evolution of a national standardised system is a huge step forward in terms of safety for babies, children and young people.

Standardised system

Ms Eyre worked for many years at the Birmingham Women's and Children's Hospital NHS Foundation Trust, which was one of the early developers of a PEWS with work that started about 15 years ago. The trust's chart forms the basis of the national PEWS, with contributions from other English charts and further development from the national System-wide Paediatric Observations Tracking (SPOT) transformation programme.

Ms Eyre says: 'It's particularly useful to support staff at district general hospitals who typically have fewer specialist paediatric staff. It means that if they need to refer patients to specialist children's hospitals, we are all using the same system, which will improve that communication.'

When it comes to rolling it out, many hospitals will have to make changes to their own locally developed systems. Some will already use a similar system, while for others it will be a much bigger change, the RCPCH says.

For those staff who need to embrace a more significant change, this 'can be and feel uncomfortable' the college acknowledges.

Pilot programme

Alice Cook, paediatric emergency matron at the Jenny Lind Children's Hospital in Norwich, helped implement the national PEWS at the hospital last year as part of the pilot programme. Introducing the new approach has meant a lot of training for staff to ensure the tool is used consistently, she says.

'The most challenging aspect to introduce at our trust was the inclusion of blood pressure, which we didn't used to routinely measure at all observations, so that was a big piece of work for us,' Ms Cook says. 'We had to make sure we had the right equipment available at all beds and different sized cuffs, and training staff so that it was consistently carried out.'

The new chart is not mandated, but will become the standard of care taught to

A nurse's intuition and clinical experience helped a child in pain

A two-year-old child who had just come round from abdominal surgery carried out with an epidural seemed quiet and withdrawn. The PEWS was carried out and it flagged up that his blood pressure was a little high.

'His mother wasn't too concerned as he had just had surgery,' says Alice Cook, paediatric emergency matron at the Jenny Lind Children's Hospital in Norwich. 'But the nurse wondered if it could be a sign that his pain wasn't being well managed.'

Pain relief

The nurse contacted the pain team, who visited the child, did an assessment and prescribed some extra pain relief.

'His blood pressure quickly went down and he became much more relaxed and communicative. The nurse was using their intuition and clinical experience, which the chart backed up, to escalate their concern. This improved the patient experience by reducing pain and could have helped them recover more quickly. It helped this child get good, holistic care.'


Neil O'Connor

The Paediatric Early Warning Score allocates points to observations, including for heart rate, respiratory rate, extent of respiratory distress and blood pressure

nursing and medical students. Hospitals that do not adopt it will increasingly be outliers.

Trusts are expected to appoint an education or implementation lead who will begin to support their trust to roll out the national PEWS.

NHS England says the new charts should be used following completion of the associated e-learning module.

Welcome change

Ms Cook says the new system has been a beneficial and welcome change that has been embraced by staff.

'For nursing staff and healthcare assistants, especially those who are more junior, it equips them with that permission and the evidence to ask for a review.'

About 80% of escalations from the new chart so far have related to the PEWS score, with the rest related to the other triggers of parents and staff concern or consciousness level, she says.

'We do escalate a bit more with this than our old system,' Ms Cook says. The routes set out for escalating, which vary according to the level of concern, highlight the importance of the role of the nurse in charge, she says.

The detailed chart includes advice to staff to escalate their concerns using the ISBAR (introduction, situation, background, assessment and recommendation) approach to identify themselves. There is a template conversation on the chart to act as a guide.

Teams of champions

The chart also prompts staff to consider if a patient could have sepsis, and to escalate if there is any suspicion that such could be the case.

When it comes to rolling out a new or altered PEWS, Ms Cook advises gaining acceptance from the whole of the multidisciplinary team. 'Get a team of champions trained in PEWS to help you,' she says.

The chart is just the beginning of the national PEWS, according to the RCPCH. Working groups are already looking at how it can be extended to emergency departments, ambulances and the community.

Future work will address whether there are ways to enable and encourage children and young people to escalate their concerns, the college says.

While it has been a long journey, children's and young people's nurses are enthusiastically embracing the new system. Ms Eyre says: 'The national PEWS is the most impressive thing that we've done collectively for quite a long time and it will save lives.'

Further information

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NHS England (2023) National Paediatric Early Warning Score (PEWS). **tinyurl.com/NHSE-pews**

NHS England (2023) National Paediatric Early Warning System (PEWS) Observation and Escalation Charts. **tinyurl.com/NHSE-pews-charts**

Royal College of Paediatrics and Child Health (2023) RCPCH Conference 2023: PEWS Session. **tinyurl.com/RCPH-pews-session**

What does the PEWS chart contain?

The PEWS chart contains multiple elements:

- A PEWS score made up of heart rate, respiratory rate, extent of respiratory distress, blood pressure, oxygen saturations, oxygen delivery and capillary refill time
- Other vital signs and observations, which do not score but must be recorded, made up of temperature, AVPU (alert, voice, pain, unresponsive) and pain score
- A parent concern trigger
- A clinical intuition trigger

There are four escalation levels (low, medium, high, emergency) which are activated by any of four triggers: the PEWS score, the AVPU level, the Parent Concern Trigger and the Clinical Intuition Trigger.

This means even if a child has a low PEWS score, the nurse reviewing them can escalate on the nurse's level of concern alone. It also allows parents to have an independent role if they are concerned about their child.

The approach is described as a system rather than a score, as while it contains a score it also provides a standardised escalation response and suggested communication approaches.

Source: Royal College of Paediatrics and Child Health (2023)

How can nurses improve mental health services for children?

There has been a steep rise in mental health referrals for children and a lack of capacity to deal with it. Dual registration could be the answer

By Pavan Amara
nurse, midwife and health journalist

More dual registered nurses must be trained to cope with a dramatic increase in the number or children with mental health issues, say senior nurses. They say that vulnerable children's needs are not being met, as young people with mental health needs are being forced into 'overwhelming' adult mental health settings or into general children's wards that struggle to provide appropriate care.

To deal with the scale of the issue, universities must run more courses that train nurses to work with children and in mental health, says Barts Health NHS Trust director of nursing for children Kath Evans.

'One reason that universities are not offering more dual training programmes nationally is because providers aren't asking for them,' she says.

'We need to be better at saying we need these programmes because our emergency department (ED) doors are open 24/7, and an increasing number of young people with mental health issues are coming in.'

Self-harm and suicide

In the year to March 2023 there were 21,555 urgent children's referrals to mental health crisis teams, up 46% compared to 12 months earlier, according to the mental health charity YoungMinds. These children were experiencing acute mental health symptoms and would otherwise need to attend hospital for psychosis, severe self-harm or suicide attempts.

Data suggest the COVID-19 pandemic and associated lockdowns may have played a part in the high numbers of young people experiencing mental health problems.

Figures from YoungMinds show that one in six children, aged five to 16, had a probable mental health problem in 2021, compared to only one in nine in 2017.

At the same time, 83% of young people with mental health needs agreed that the pandemic had made their mental health worse.

Mental health nurses say the increase is more complex than that, however, with many factors needing to be considered. Barts Health NHS Trust children and young people's mental health practice development nurse Amina Marzouki says that in her trust's area of London, social and economic factors all contribute to increasing

mental health problems among young people.

'With social media like TikTok and Instagram there is this false idea of living a luxurious life,' she says. 'There are also many horrible websites that teach young people to inject insulin to lose weight and encourage anorexia.

'There are gangs that recruit young people in years five and six (aged nine to 11) to deliver drugs, and consuming drugs is common in children around the age of 12.

'The cost-of-living crisis has increased that pressure on some children to bring money home. There is also bullying and dysfunction in families, so there are many factors apart from COVID.'

Lack of trained staff

Ms Evans says that, although an increasing number of young people are attending the ED with mental health issues, a lack of staff trained in children's and mental health nursing means that 'capacity to deal with this is poor'.

'A lot of young people admitted into hospital with mental health issues are having to spend time in general children's settings or adult mental health settings,' she says.

'Adult settings are overwhelming for them. Their needs as children can't always be met. Dual registrants would bring a degree of flexibility – we'd have more choice in terms of where children are cared for, we could meet their holistic needs in those places and safeguarding would improve. It would make a significant difference.'

'If we had a few dual registered nurses in each children's ward it would make a significant difference to the service, and it would also encourage staff to be more thoughtful about what they're doing'

Kath Evans, director of nursing for children, Barts Health NHS Trust

Ms Marzouki, who initially trained as an adult mental health nurse (RMN), agrees that dual registrants would have a better understanding of safeguarding needs.

'Most children's nurses don't have experience of caring for those in mental distress, and most RMNs have little experience with children. As a result, RMNs tend to find safeguarding difficult with children.

'If a child makes an allegation of something, it's different to if an adult does, and some RMNs don't feel as comfortable handling that as they would with adults. It's possible that dual registration could improve safeguarding and safety overall.'

Greater registration

There has been an increase in the number of children's nurses registered with the Nursing and Midwifery Council (NMC) over the past decade, and in mental health nurses registered since 2014. This year there are 95,485 RMNs and 57,014 children's nurses registered with the NMC.

These numbers do not necessarily reflect those in permanent roles or employed by NHS services. But Lewisham and Greenwich NHS Trust head of nursing for mental health Kevin Ramjeet says that RMNs coming into the workforce will not necessarily be well equipped to care for children.

'When you're doing RMN training, you might get an eight-week placement in an adolescent unit, but that does not equip you.

'Different dynamic'

'I worked in adult mental health and thought working with children would be a walk in the park. It was not.

'It was the toughest place I've worked. I thought I was resilient and knew what to say, but all that went out the window in a few weeks.

'There is a different dynamic with children. There were 14 or 15 children on the ward I worked on and they all had their own issues; they all compete for your attention as a nurse in a different way to what adults would normally do.

'You are often working more with children's families than you would be with the families of adult patients. That takes different skills; there can be a lot more emotion involved.

'The things you say have to be thought through differently because children will often interpret things differently to adults. Things you think that are trivial, are not.

'One clinician said to a child who had been self-harming: "You are so pretty, you really don't want to be scarred for life". But that was a trigger for that child and could have led to an escalation. Understanding mental health, but in the context of adolescence for example, is important.'

He adds that RMNs and children's nurses may find

Tips for practice – working with children experiencing mental health issues

- **You don't have to resolve everything or be an expert** Come with an open mind, listen carefully and tell the patient that you will come back to them if you do not know the answer
- **Give extra time when necessary** Time is in short supply, but children are more likely to engage if you do not appear rushed, and this can make a difference to receiving crucial information
- **Go at the young person's pace** Some young patients may be interacting with mental health services for the first time – when they disclose their experiences, say thank you for sharing and give them a moment before asking key questions
- **Think about language** Official terms can alarm or confuse younger people as they may be less familiar with them compared to adult users of mental health services. When using words like 'acute', for example, explain what that means

Source: Collated from interviews with the Barts Health NHS Trust and Lewisham and Greenwich NHS Trust nurses quoted in this article

children's behaviour 'surprising' when they have mental health issues.

'There can be an assumption about children's mental health,' he says. 'So, when they see children smashing up a computer, self-harming, swearing and shouting, they won't understand this is behaviour that they have learnt. General children's nurses won't be used to seeing this behaviour and RMNs won't necessarily see the child's trauma behind the behaviour.'

The main barrier to employing more staff who are children's and mental health nurses, adds Mr Ramjeet, is that there are not many available, as dual training takes more time and money.

'You would have to do a three-year course and then an 18-month course to be dual trained,' he says. 'It takes money to do that, but the starting salary won't be any higher.

'If there is one course to train in both areas, then that course may be longer, maybe four years, so those doing it are in the same situation of spending more time training but not having higher starting salaries.'

'Glimmer of hope'

Lewisham and Greenwich NHS Trust's head of nursing for children and young people Robert Cole says there is a 'glimmer of hope' with nurse associates, as they can be trained across mental health and children's settings.

'They would be able to carry out mental health interventions with children, consider developmental milestones and work with families too,' he says.

'Realistically it would be good to have dual trained nurses but, unlike adults, you see peaks and troughs with children's mental health. Some dual trained nurses might find it unattractive to work in a paediatric area during those periods where they're not using their mental health skills.'

Dual trained nurses would help improve care for children with mental health issues

There are 95,485 RMNs and 57,014 children's nurses on the Nursing and Midwifery Council register in the UK. This number does not necessarily reflect those in permanent roles or employed by NHS services.

Last year, NHS England says it boosted staffing numbers in England's children's mental health services by 4,500, or about 40%, but how many of these were nursing jobs is unclear.

A handful of undergraduate and postgraduate courses enable registration as a children's and a mental health nurse, including those at the University of West London, University of Leicester, the University of Birmingham, Dundee University and Anglia Ruskin University.

Ms Evans says the opportunity to register as both needs to be extended. 'If we had a few dual registered nurses in each children's ward it would make a significant difference to the service, and it would also encourage staff to be more thoughtful about what they're doing.'

Ms Evans' colleague at Barts Health NHS Trust, associate director of safeguarding Clare Hughes, has overheard mistakes being made when nurses who are not dual registered care for young people with mental health issues.

'I have heard comments like: "They just need to get on with it" or: "They really just need to get a grip",' she says.

'That doesn't happen across the board, but if there was more mixed educational opportunity in children's and mental health nursing that would improve.

'We have heard staff tell young people they must be seen with a parent and that young person has disengaged as a result.

'This is a lost opportunity because if that young person can access care now, then their mental health is less likely to deteriorate as they enter adulthood and develop into behaviour that then requires more care.'

Language and tone

People aged over 16 do not need to be seen with a parent and children under 16 can consent to their own treatment if they are Gillick competent. Ms Hughes says that insisting young people are seen with a parent could cause them to disengage.

'At the same time, you do need to ask about parents to pick up on safeguarding issues,' she says. 'If they tell you they're not living at home, then where are they living and with whom?

'Safeguarding is about listening, but also asking key questions without pushing. It's a fine line. You need to keep children in hospital to do the interventions and that means keeping them calm.

'But if you phone someone like me for advice, I need to know enough about it to give you the correct advice. It' s often about how you ask children uncomfortable questions, the language and tone you use matters.'

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Young Minds (2023) Mental Health Statistics. **tinyurl.com/YM-mental-health-statistics**

Glucose monitoring for type 2 diabetes in children

Continuous glucose monitoring is now recommended for some young people with type 2 diabetes

By Allie Anderson
health journalist

Continuous glucose monitoring (CGM) has been a mainstay in managing type 1 diabetes in children and young people since 2015 but the technology is less widely used among patients with type 2.

New guidance for management of type 2 diabetes in children

In May 2023, the National Institute for Health and Care Excellence (NICE) updated its guidance on diabetes management in children and young people. It recommends using real-time CGM (rtCGM) or intermittently scanned glucose monitoring (isCGM, or 'flash' monitoring) devices for some children with type 2 diabetes who meet certain criteria. They include:

- Patients on insulin.
- Those who have episodes of dangerously low blood sugar.
- Those who would need to test their blood sugar eight or more times a day.
- Those who have a condition, such as a learning disability or mental health needs, that makes it harder for them to do finger-prick testing.

What are rtCGM and isCGM?

With both types of CGM, the patient has a small sensor attached to their body, which detects and reads their blood sugar levels and sends the data to a monitoring device or a smartphone.

'With an rtCGM the latest sugar levels are transmitted automatically via Bluetooth to the chosen device, whereas with isCGM people can only see their sugar readings once they have scanned the sensor with their phone or reader device,' explains Esther Walden, a diabetes inpatient specialist nurse and Diabetes UK's deputy head of care.

'There was recently an update to the isCGM software, meaning for those using phones instead of readers, the device will now work as an rtCGM if they chose to install the update.'

What are the benefits for children with type 2 diabetes?

Traditionally, people with diabetes would have to undertake finger-prick testing several times a day to check their blood glucose levels and this can be painful and distressing for children. CGM is a less invasive alternative.

According to Sheffield Children's Hospital children's diabetes nurse specialist Emma Loader CGM brings benefits for patients and for their healthcare team.

'Data from the patient's CGM can be sent automatically to the clinic so we have information 24/7, which we can analyse and use to make changes to their medication if needed,' she says. 'It also means we can give advice over the phone rather than the family having to come into the clinic.'

CGM can also empower teenagers with diabetes – who are typically harder to engage – to discreetly take control of their condition. 'Teenagers always have their phone on them, so they can easily check their blood sugar without having to carry a blood sugar monitor around and do their finger-prick tests in front of their friends,' Ms Loader adds.

CGM can be set up to sound an alarm on the child's or their parent's phone if the patient's glucose levels go too high or low. 'This means they can be proactive and respond to readings in real time, rather than having to reactively respond when they take a random finger-prick sample,' says Ms Walden.

Crucially, CGM can support young people to self-manage their condition. 'Being able to see sugar levels continuously allows people to observe how different food or activity affects them, enabling them to make meaningful, individualised changes to their lives.'

'Our role is to educate patients and families about what different foods do to their blood sugar'

Further information

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NHS Digital (2021) Young People with Type 2 Diabetes, 2019-20. **tinyurl.com/NHSD-young-people-type-2**

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Royal College of Paediatrics and Child Health: Diabetes. **tinyurl.com/RCPCH-child-diabetes**

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Can CGM devices improve health inequalities for children with type 2 diabetes?

Data suggest that children from minority ethnic and socioeconomically deprived backgrounds have poorer diabetes outcomes. There is also evidence that these patient groups experience inequality of access to diabetes technologies, such as CGM.

With healthcare teams able to see data shared directly from the patient's CGM, they can manage changes remotely and be less reliant on face-to-face consultations. 'This can help reduce the financial burden of attending appointments and potentially increase access to healthcare,' says Ms Walden. However, nurses may face resistance when first introducing CGM. 'We have a lot of deprivation in Sheffield, and many different nationalities and ethnicities.' explains Ms Loader. These groups can be considered digitally excluded, meaning they may lack the access, skills and capabilities needed to engage with technologies.

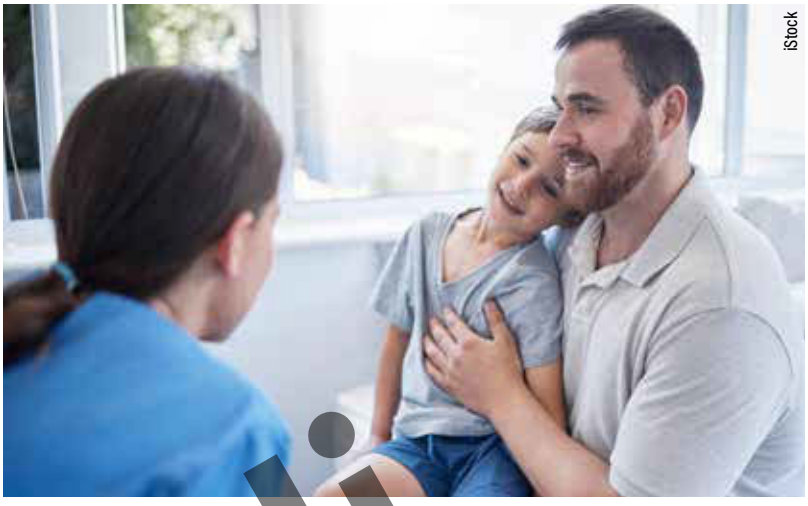
Although not within the NICE recommendations, type 2 patients at Ms Loader's service are offered CGM at the point of diagnosis when, she says, patients and families are more open to discussion. 'Our role is to educate them about all the options, and about what different foods do to their blood sugar. At diagnosis they are like a sponge, ready to soak up all that information and they are more likely to engage,' she adds.

The team finds creative ways to overcome language barriers and support uptake among harder-to-reach groups. For example, when demonstrating how to use the CGM device and change the sensors, they encourage families to record it on their phones. They also provide some information in picture format, use online translation tools and work with interpreters when needed.

Could there be any issues with the supply of CGM?

Type 2 diabetes in children is not common – fewer than 1,600 children and young people under the age of 19 in England and Wales were reported to have the condition in 2019-20.

Ms Walden says that, although there is always potential for supply problems with medication and equipment, 'we do not foresee any issues with supply in relation to the guidance change. However, the devices people are offered vary depending on local contracts negotiated by integrated care boards,' she adds.



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COMMENT

Don't forget to involve the fathers in conversations

When talking to parents of children with complex needs, nurses should ensure their communication is inclusive

By Eleanor Willis
Roald Dahl nurse specialist for children with medical complexity at East and North Hertfordshire NHS Trust

Sometimes a conversation with a patient or carer can prompt us to seek change, especially when we gain insight or awareness of an issue that challenges our values as a nurse.

During a recent conversation with a family, a father shared his personal experience of caring for his child who has complex health needs. When his son is in hospital, he said, he had noticed that professionals usually directed their communication to his wife, even if he asked questions himself.

The way he spoke made it clear he was describing a style of communication he had come to expect, rather than a one-off example. His son has had frequent inpatient admissions during the past two years at various local and tertiary hospitals.

I was shocked that a skilled parent carer could feel so invisible despite being physically present – this was particularly startling in the case of this father, who had chosen to be a stay-at-home dad due to his son's health complexities.

I was grateful to him for being honest and for being open to exploring the issue further. I hope he experiences inclusive and compassionate communication with healthcare professionals in the future.

If we promote the well-being of parents who are caring for a child with complex health, they will be more able to care for their child, and the whole family will have a greater chance of thriving. When carrying out parental interviews for my own research project, I was interested that only mothers volunteered to participate, despite an open invitation to both parents. This could have been due to a variety of factors and is corroborated by under-representation of fathers' viewpoints in the evidence base. My discussion with this father prompted me to reconsider my own perceptions again, and wonder what more we can do to recognise the voice of fathers and be more inclusive.

Identity and social connection

This is important because the population of children living at home with life-limiting and life-threatening medical complexities is growing, affecting more parents as they take on increasingly skilled caring roles. This can negatively affect an individual's identity and social connection due to burdens of care and increased hospital attendance.

Evidence demonstrates that fathers who are carers in the general population are at greater risk of anxiety and depression. The health inequalities faced by fathers of children with medical complexity is underresearched. However, we know that mothers have increased physical and mental health morbidity and mortality.

Greater information about the needs of fathers would enable services to start to address them. While the voice of fathers is under-represented we do not know if a parent's gender influences their carer experience. For example, does most fathers remaining in employment lead to benefits by providing normality and increased financial security, or does it add to pressures?

We also need to consider carer experiences in relation to modern family dynamics, bearing in mind that perceived notions of gender roles may be outdated, and also that same-sex and lone parents already face social inequality.

Parental perceptions are important. Often our intention and effect during communication differ. The professionals who interacted with this dad surely had no intention of making him feel disregarded, but perhaps in children's healthcare we have an unconscious bias towards a maternal opinion, or we react to other cues and direct communication towards a parent who seems more vocal or more emotional. These points are raised as questions rather than judgements.

Anecdotally, mothers are more likely to become the primary carer for children with medical complexity, but this should not stop us including fathers. Think Carer, Think Family encourages a holistic family-oriented perspective, which benefits not only the patient but the carer. Healthcare professionals have a duty to recognise and value the voices of all carers. If we build a rapport with families, and encourage collaboration, we are more likely to minimise frustration and hostility. Respecting parents' expertise and validating their opinions is beneficial in reducing conflict, and part of holistic assessment and care.

Deeper understanding

Finding out about family members and what is important to them positively affects well-being, as well as relationships between families and staff, enabling deeper understanding.

Use of preferred names, instead of defaulting to mum and dad, is generally appreciated by families. Thinking about how key health information is handed over between parents is also useful, especially for parents whose caring roles may include a sick child in hospital and siblings at home.

Ongoing contact with families over a period of time provides an opportunity to check with parents what is going well and what could be improved, and ensure they are accessing support. Carer leads in organisations are also an excellent resource.

The father who shared his story with me had not intended to generate a bigger conversation. I expressed my gratitude for his honesty and for raising my awareness. It was also an opportunity to talk about how things can be improved in the future. Following liaison with my local carers lead I have been able to share with this father some of the work being done locally to make positive changes and make carers more visible, so that their needs are not ignored. If a carer feels seen and heard we are being inclusive, compassionate and hopefully making them feel more valued in their vital role.

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Finding out about family members and what is important to them positively affects well-being


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RCNi

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Writing for publication is all about the reader and, as an author, you want the reader to journey through your article from start to finish with as few obstacles, forks in the road and dead ends as possible. Think of the abstract as a guide to this journey.

Highlight what you think is important

An abstract explains what lies ahead, it highlights important features or findings and it describes the end point.

A well written abstract can make the difference between readers reading your article and reflecting or acting on it, and their abandoning the journey before it has begun.

Write the article before the abstract

You cannot summarise what you have not yet written. Stick to the guidelines. Abstracts in RCNi journals have between 80 and 150 words. Anything longer is likely to be cut so make every word count.

Follow the same order of topics in the abstract as you do in the article. But write the abstract separately rather than cutting and pasting chunks of text from the article.

Not too much detail

Describe your article's main arguments and findings broadly. The detail should be in the article itself.

All abstracts should be followed by a list of five or six keywords. These will help online searchers to find your article once it is published.

When choosing keywords, think about the article's subject matter, the setting, the target group of patients or clients, the healthcare professionals involved, the techniques described and so on. For example, a typical set of keywords is: 'depression', 'nursing homes', 'older people', 'community mental health nurses', 'cognitive behaviour therapy'.

What matters?

When writing the abstract, think about the article's purpose. Be clear about the issue you are trying to address. What does it add to the sum of existing nursing knowledge? How is it likely to influence nursing practice? The abstract should give readers a reason to read on. Avoid jargon and unexplained acronyms. This applies to the main text as well as the abstract, but the abstract should 'sell' the article to readers so it is important not to litter it with words and phrases that confuse and discourage.

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PEER-REVIEWED

Why you should read this article:

- To recognise the benefits of service user involvement in healthcare education for learning and practice
- To understand how grief and bereavement can affect the parents of children in palliative care services
- To identify the need to develop meaningful partnerships between academics and service users to achieve authentic, person-centred healthcare education

Evaluation of service user-led workshops in children's palliative care education

Joanne Pavey, Julie Kembrey and Antonia Beringer

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Abstract

Children's nurses report feeling unprepared when caring for children with life-limiting conditions and their families, while the value of including service users in the provision of nursing education is increasingly recognised. This small-scale service evaluation examined the effect on learning of service user-led workshops as part of a module for final-year children's nursing students and post-registration children's nurses. The workshops focused on the experience of children's palliative care and child bereavement from the parents' perspective. Findings from evaluation data indicated high levels of satisfaction with the workshops and identified three themes: safe space, shift in perspective and enhancing practice.

A model of service user facilitated learning describes how these themes can enable learning about children's palliative care. This evaluation suggests that the involvement of service users as partners in healthcare education can be transformative, enabling children's nursing students to examine their own perspectives and consider ways to enhance their future practice.

Author details

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Keywords

bereavement, child health, clinical, education, end of life care, grief, palliative care, post-registration education, pre-registration education, professional

Background

The provision of safe, compassionate and effective nursing care, which is also evidence based and person centred, requires service users to be involved in the design, delivery, evaluation and co-production of educational programmes (Nursing and Midwifery Council (NMC) 2018) and is mandatory in UK health and social care degree programmes (Scammell et al 2016).

UK healthcare policy has long recognised that service users are 'partners in care' and this should be reflected in practice (Department of Health 2012). Meaningful service user partnership in the education of healthcare professionals is central to contemporary healthcare to defend against suboptimal quality care and fatal failings (Francis 2013, Tobbell et al 2018). The value of partnerships between healthcare professionals and service users throughout healthcare delivery and education was evidenced in the Keogh review (Keogh 2013), which assessed the quality of care and treatment at 14 hospitals in England with higher-than-expected mortality rates. The Keogh review reinforced the importance of putting the voice and experience of service users at the centre of healthcare professional education. This view was supported by evidence from Atwal et al (2018) who suggested that embedding high-quality service user involvement in nurse education, although challenging, is seen as beneficial (Scammell et al 2016).

Key points

- Service user involvement in nurse education supports the facilitation of learning
- Listening to service users' experiences can develop compassion in nurses and lead to improvements in person-centred care
- There is a gap in the literature concerning how service users facilitate learning and whether practice is affected long term, which provides scope for a larger scale study

While the benefits of service user involvement in facilitating learning are well documented (Felton et al 2018), the term 'involvement' is ambiguous and inadequately defined (McCutcheon and Gormley 2014). One way to conceptualise involvement is offered by the five-level Ladder of Involvement model (Tew et al 2004), where level one represents 'no involvement' and level five represents 'partnership'. While the model has limitations due to challenges in interpretation, its underlying principles of avoiding tokenism while providing authentic service user engagement are recognised by Scammell et al (2016) as being 'mutually beneficial' to service users and learners.

Felton et al (2018) offered more detail about the benefits of service user participation to learners, revealing that students valued it because they found it an engaging, enjoyable and positive experience. Specific benefits such as improved communication, and increased empathy and understanding were identified by Gordon et al (2020), particularly when service users were seen in an active role as educators rather than as passive recipients of healthcare. As a result, Tobbell et al (2018) identified that service user participation could contribute to improved collaborative working partnerships between professionals and service users. In contrast, Speed et al (2012) reported that there are individual and organisational barriers to meaningful engagement that need to be considered when setting up collaborative working partnerships.

A distinct gap exists in the literature regarding how service users can support nurses to learn (Cheng and Towle 2017). Some studies have begun to explore pedagogical approaches to map outcomes and explain why certain interventions are effective (Gordon et al 2020). They suggested that sociocultural learning techniques, such as skilled narrative storytelling, can bring a humanistic perspective to care and can be transformative (Jack 2020).

In a study of interprofessional perinatal and neonatal palliative care education, Price et al (2019) found the inclusion of a bereaved mother's personal experience was the single most memorable event of a workshop. The researchers suggested that exposure to first-hand experience could lessen nurses' anxiety about child death and bereavement and in doing so remove barriers to learning. Kuti and Houghton (2019) evaluated their Patient as Coach Team (PaCT) initiative and found it offered a 'valid learning strategy' for students to reflect on their practice and learn from service users' experiences and perspectives of care. However, there is limited evidence to show whether actual changes in practice or patient care result from service user involvement in teaching (Morgan and Jones 2009).

This article presents a service evaluation of grief and bereavement workshops delivered by service users as part of a children's palliative care module for pre and post-registration children's nurses at a university in south west England. The evaluation includes the experience of post-registration children's nurses, a group identified by Gordon et al (2020) as under-represented in previous studies. The evaluation contributes to evidence on the benefits of service user involvement in healthcare education by examining how such involvement may have a positive effect on learning and how this may enhance practice.

Aim

The aim of the evaluation was to examine and share feedback from service user-led workshops and contribute to existing studies of service user participation in healthcare education.

Method

Workshop design and delivery

The grief and bereavement workshops were designed, developed and delivered by bereaved mothers (JP, JK) of children with life-limiting conditions, drawing on their personal experience of children's palliative care services and bereavement support and informed by their backgrounds in public speaking, fundraising, group facilitation, trusteeship and training. The workshops addressed aspects of caring for children with a life-limiting condition, end of life care, child death, bereavement and models of grief, from the parent perspective. Group work and opportunities for discussion were used to engage the pre and post-registration children's nurse students (Box 1), providing a chance to explore a sensitive topic in an open and supportive way.

The aim of the workshops was to develop empathy and facilitate communication between families and nurses about the child with a life-limiting condition. The workshop content was based on first-hand accounts of real-life experience from two contrasting examples of grief and bereavement.

Participants

A total of six workshops were held between December 2016 and November 2019. The 111 participants comprised preregistration nursing

students (n=84) who chose the module in the final year of their nursing degree programme and post-registration children's nurses (n=27) for whom the module was part of their continuing professional development (Table 1).

Evaluation

The evaluation form used in the workshops included questions that invited quantitative and qualitative responses (Table 2). Numerical scoring indicated how participants rated the workshop and free-text comments invited a more detailed response (Mertens 2018). Evaluation forms were distributed by the facilitators at the end of each workshop and completed anonymously by participants.

Data analysis

Scores from the evaluation forms were manually entered into Excel and collated to provide a descriptive numerical representation of the data.

Qualitative data, in the form of free-text responses, were transcribed and analysed using the process of constant comparison to generate initial codes and to identify themes (Braun and Clarke 2006). Analysis involved individual reading and rereading of the transcribed extracts, and discussions between the service users (JP, JK) and the module leader (AB), to seek agreement on the meaning and interpretation of the data. Through this iterative process, three themes emerged – safe space, shift in perspective and enhancing practice. These three themes were seen to be related in a sequence, with one theme leading to the next. By being in a safe space the participants were able to experience a shift in perspective, which could then potentially enhance their practice. This implied the need for a model, which could be used to represent the sequential relationship of themes, to facilitate learning. Such a model was subsequently designed by the authors.

Ethical considerations

As this was a service evaluation, formal ethical approval was neither required nor sought. The evaluation was, however, conducted in observance of ethical principles: enabling the choice to participate (autonomy), involving all participants (justice), maintaining anonymity and conducting the workshop in a supportive way (non-maleficence) (Gillon 2003).

Findings

Quantitative results

Participants across all workshops gave scores of four or five (the two highest options) and two scores of three, in response to the three evaluation questions (Figure 1).

Comparing overall ratings by preregistration and post-registration participants showed that a similar proportion gave scores of four or five, suggesting that both groups found the workshop equally useful (Figures 2 and 3).

Qualitative findings

Analysis of the free-text responses identified three themes: safe space, shift in perspective and enhancing practice.

Online archive
For related information, visit **nursingchildrenandyoungpeople.co.uk** and search using the keywords

Box 1. Workshop design and delivery

Design:
- Case studies based on experience of facilitators, and family experiences from Lives Worth Living (Cotter 2014)
- Consideration of safeguarding of participants due to sensitive nature of the topic
- Built-in opportunities for interaction, group work, feedback, discussions and questions

Preparation:
- Ensuring the learning environment was welcoming and private
- Safeguarding of facilitators: through working partnership, self-support and supervision
- Safeguarding of participants: permission to leave workshop if necessary and return when ready. Access to course leader for extra support during and after session

Delivery:
- Course leader introduces facilitators and hands over to the group
- Facilitators outline the session including aims, structure, breaks and invite students to interact throughout the workshop
- Accounts of lived experience along with informal slides and photographs
- Facilitator's perspective of grief models, relevant research and statistics
- Signposting suggestions
- Question-and-answer session including encouragement of peer support

Closing:
- Tips on self-care in acknowledgement of emotional content
- Course leader re-joins group at the end of the workshop to pick up on any issues
- Evaluation sheets filled in and returned

Follow-up:
- Facilitators' debrief
- Facilitators read evaluation sheets
- At the end of the module, the course leader shares feedback from students with the facilitators to track the value and reception of the workshop

Table 1. Workshop participants

Workshop	Date	Course type	Participants (n)
1	December 2016	Preregistration	23
2	November 2017	Preregistration	24
3	March 2018	Post-registration	20
4	November 2018	Preregistration	15
5	March 2019	Post-registration	7
6	November 2019	Preregistration	22
Total			**111**

Safe space

Participants described the importance of the creation of a 'safe space', which enabled them to engage with the sensitive nature of the topic:

'You created a very special atmosphere which made me feel safe to ask questions and share thoughts.' (Participant 3, workshop 1)

'Excellent, very moving presentation. Really felt connected with you both. Emotive, passionate and full of love… more people need to hear this!' (Participant 12, workshop 3)

Shift in perspective

Participants reflected back insights that described a greater and deeper understanding of what the experience of caring for a child with a life limiting condition, child death and bereavement is like for the families they encounter:

'I have gained an appreciation of how long grief will last and how deep it will go.' (Participant 23, workshop 2)

'I have worked in palliative care for many years and this session is the first time I have really "heard" what it is like for families through their journey.' (Participant 2, workshop 3)

'It really opened my eyes to what it can be like for the family.' (Participant 7, workshop 6)

Participants also offered reflections describing a greater understanding of the influence they could have on the experience of families:

Table 2. Evaluation questions

Questions	Format – scored 0-5 (with 0 lowest and 5 highest) or free text
Q.1. How would you rate this workshop?	0-5
Q.2. Did you gain any new information?	0-5
Q.3. Did you gain any practical ideas or information to use in your day-to-day practice?	0-5
Is there anything you would like to add to the workshop?	Free text
Any further comments?	Free text

Figure 1. Collated answers (0 = lowest and 5 = highest) of both pre and post-registration participants to the three questions on the evaluation form (n=111; with one non-response to question 3)

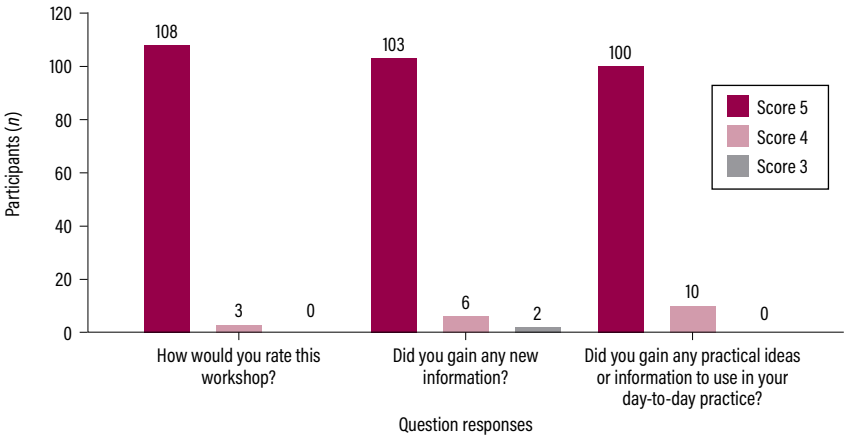


Figure 2. Collated scores (0 = lowest and 5 = highest) from preregistration participants (n=84; a total of 251 questions answered, with one non-response to question 3)

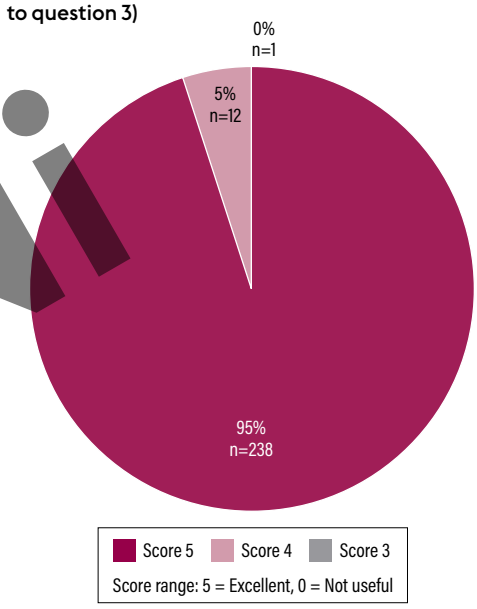
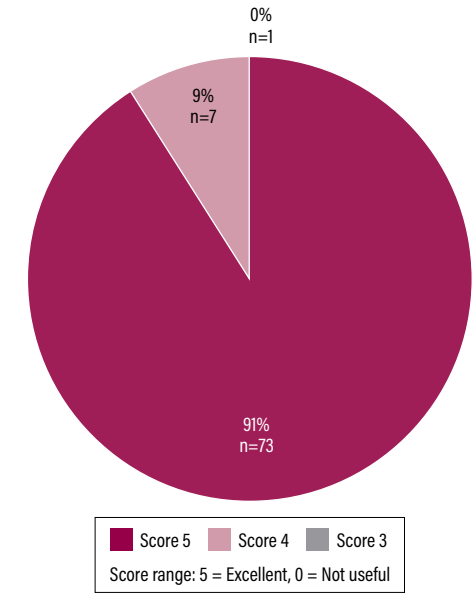


Figure 3. Collated scores (0 = lowest and 5 = highest) from post-registration participants (n=27; a total of 81 questions answered)



'I learned a lot about what makes a good experience in a bad time and how as nurses we can help parents.' (Participant 7, workshop 1)

'You made me feel a range of emotions and provoked thoughts about how I can better myself as a children's nurse.' (Participant 14, workshop 1)

Participants also recognised that the insights gained by this shift in perspective would be valuable to their work in other areas of nursing, in addition to children's palliative care:

'… it would be good to have this in our general curriculum, not just [the] palliative module.' (Participant 19, workshop 2)

Enhancing practice

Participants identified ways they could take back and apply what they had learned to their own practice:

'Helps to reflect on my own practice and ways to move the service forward.' (Participant 5, workshop 3)

'… it has really changed my view of care.' (Participant 17, workshop 1)

'I will take forward everything you've said in my career, and I hope to be that nurse a family remembers.' (Participant 7, workshop 4)

Some participants offered general comments on the workshops, as well as providing specific ideas and improvements that could enhance communication, empathy and engagement between families and staff:

'I would be much more confident in how to lead discussions, comfort and advise parents in bereavement scenarios.' (Participant 10, workshop 4)

'It is a good reminder of how the small things can be forgotten and make a difference to the memory of a child for their family. Also, what a difference we can make when we may feel powerless to help.' (Participant 10, workshop 3)

'Very moving accounts yet uplifting… just having an idea of what to say/do, for example just holding a hand – making a cup of tea is enough sometimes. I gained advice, tips and confidence in helping and supporting parents during difficult times.' (Participant 24, workshop 2)

'It would be interesting to get a perspective on fathers and male carers.' (Participant 1, workshop 3)

'It would be good [for the workshop presenters] to provide information on support available to families along the journey.' (Participant 16, workshop 6)

Analysis revealed that several participants' feedback contained all three themes (safe space, shift in perspective, enhancing practice), for example:

'Both speakers were very approachable and allowed me to feel comfortable talking about such a difficult subject [safe space] … the session has made me realise how much us as nurses can influence how parents feel during situations [shift in perspective] … and how a kind word can be the difference in someone's day' [enhancing practice]. (Participant 13, workshop 4)

Overall, the participants' responses inferred that the three themes were sequentially interrelated and could be used to provide structure for a linear model of learning, facilitated by service user involvement (Figure 4).

Discussion

The components of the model of service user-facilitated learning shown in Figure 4 are discussed here in the context of attempting to understand how best to provide service user involvement in healthcare education.

Safe space

The first component of creating a 'safe space' to explore the sensitive topic of child death and bereavement was identified by participants as an important aspect of the workshops. Factors that contributed to developing a safe space included acknowledging the emotional content of the subject matter, giving permission to ask direct, 'challenging' questions and to take time out with support if needed, alongside some practical advice on self-care. The workshops (see Box 1) included a range of activities designed to encourage participation and group engagement and support active learning. Having a clear structure, which made explicit the direction and duration of the workshop, supported participants to navigate it and contributed to their feelings of safety (Holley and Steiner 2005).

The service user facilitators contributed to the safe space with their confidence in the content and delivery of the workshops. They were supported but trusted to teach independently and were paid for their contribution. This provides an example of level five 'partnership' on the Ladder of Involvement model advocated by Tew et al (2004). Rather than being seen as passive recipients of care in a clinical environment (Jack 2020), the knowledge, strengths and

Figure 4. A model of service user-facilitated learning

abilities of the service user facilitators were recognised. As a result, participants engaged openly with the sensitive topic of child death and bereavement and were able to ask questions and enter discussions without feeling responsible for the service users' well-being. This type of active involvement, with questions and dialogue, is important for deepening learning and knowledge (Jack 2020), is mutually beneficial and reflects findings by Atwal et al (2018) where service users feel valued, listened to and respected, fostering a sense of altruism.

Shift in perspective

The next component of the model, a 'shift in perspective', may have been enabled by the core content of the workshop: the service user facilitators' personal experience of children's palliative care. Listening to service users' stories and understanding their perspective was shown by Durkin et al (2019) to develop empathy and compassion. The openness of the facilitators in relating their experiences of child death and bereavement in the workshop enabled participants to 'open up to' and 'feel' the facilitators's vulnerability while also witnessing their resilience.

In this evaluation, participants reported feeling 'moved' and were comfortable enough to experience this due to the autonomy and confidence of the speakers and the safeguarding in place. Gordon et al (2020) described how this emotional response evoked from patients' narratives of lived experience could help develop deeper meaning to academic concepts.

The workshops also gave opportunities for reflection on personal perspectives, beliefs and experiences. This enabled participants to consider the effect of their own practice on service users and challenged them to consider what person-centred care means (Atwal et al 2018). The humanistic pedagogical approach adopted by the workshop facilitators included, but also moved beyond, the well-recognised effect of storytelling, by encouraging interaction and group sharing, which increased the potential for learning (Cheng and Towle 2017). Hearing stories about the joy and pain of children's palliative care offered participants a deeper understanding of what daily life is like for the children and their families. This is vital in developing compassionate nurses who can provide individualised and responsive person-centred care (NMC 2018).

Delivering authentic and powerful narratives in person and in real time to facilitate learning challenged the traditional relationship dynamic between service users and healthcare professionals. It enabled shifts of perspective, which provided deeper understanding and empathy towards service users and made sense of the theoretical content of the module. This reflects the findings of Jack (2020), which identified that in service user-facilitated sessions, the traditional didactic approach of being 'taught to' became a co-developed learning experience which could be liberating and transformative.

Enhanced practice

The final component of the model considered how the workshops supported participants' intentions and aspirations to 'enhance practice'. This was promoted by encouraging participants to reflect during the workshop on their own experience of offering palliative care to children and families alongside their peers. The evaluation responses showed that they had already begun to apply their learning by sharing ideas about practice improvement. Examples included developing the therapeutic use of self, by being present with a grieving family, not feeling the need to 'fix' things, showing small acts of kindness and listening for sometimes unexpressed need. These skills are relevant across all areas of nursing practice and especially useful in children's palliative care where no cure is available. They empower nurses to provide high-quality compassionate care and increase engagement and confidence in the provision of bereavement support for children and families.

The participants expressed a realisation that their presence and kindness could have a significant effect in challenging times. They described an increased confidence, particularly in communicating and managing sensitive situations with deeper understanding, which they would use to shape their future practice.

Statements from the participants about 'seeing things from the family perspective' echo the findings of Rhodes (2013), in which the development of empathy – not just for the child who is at the centre of care, but for the whole family as a unit – could result in enhanced planning, decision-making and communication. This could lead towards a more collaborative partnership approach to care, as described by Tobbell et al (2018), who found that with this approach students experienced an identity shift towards more equal patient partnership. This encouraged a willingness to share information and collaborate in decision-making.

Engagement with service user stories also enabled participants to critically reflect on and develop their practice with renewed empathy to potentially change and challenge negative stereotypes (Jack 2020).

There is little evidence, however, to show that such learning and empathy is fully embedded beyond the session or has any effect on behaviour in practice (Gordon et al 2020). The findings presented here suggest that the intention to improve practice was initiated, but whether this was put into practice falls beyond the scope of this evaluation.

Some studies suggest that empathy declines in nursing students as their degree progresses and is not transferred into professional practice (Heidke et al 2018), having little direct effect on patient care. There is some evidence to suggest that early introduction of empathy education heightens nurses' self-awareness and self-care (topics that were included in the workshops in this evaluation). This, in turn, may prevent burnout and develop a basis from which empathy can be embedded and extended to others. Kuti and Houghton's (2019) study, focusing on service user pedagogy, provided evidence that increased interaction with service users throughout healthcare education and settings leads to an increased commitment to care and an aspiration to positively change behaviours in practice.

Nonetheless, even if empathy has been embedded and perspective shifts have occurred there can still be barriers to positive patient outcomes. Service users' opinions may be counter to that of managerial and organisational policy, which could lead to divided loyalties and conflict. To minimise this, service user involvement should be standard practice in all areas and levels of healthcare education to realise the aims and intentions of a healthcare system that is truly person-centred and compassionately responsive (Zanbar 2018).

To enable the involvement of service users in nursing education, individual and organisational barriers must be addressed. Individual barriers for service users can include work commitments, caring responsibilities, health considerations, logistical aspects and the confidence and desire to take part. Recounting lived experience can be empowering but it can also be emotionally exhausting and re-traumatising for some, suggesting that the service user's needs and well-being should be considered (Gordon et al 2020). This identifies the significance of a safe space to safeguard students and to protect service users, especially when delivering a sensitive topic.

Organisational barriers to service user involvement in nursing education can include the lack of recognition of the need for remuneration and training for service users (Tremayne et al 2014), which can reinforce a tokenistic approach, whereby service user expertise remains an untapped resource (McCutcheon and Gormley 2014). Overcoming these organisational barriers will involve addressing a lack of commitment and investment in service user engagement at a strategic level.

This evaluation provides an example of authentic engagement and a meaningful partnership (Felton et al 2018), which avoided the tokenism acknowledged by Scammell et al (2016). The evaluation demonstrated a high level of engagement on the Ladder of Involvement (Tew et al 2004) and can be seen as an example of movement towards service user-healthcare professional partnership models (Tobbell et al 2018) in which the service user has an active role as educator while retaining autonomy and authenticity with direct benefits to students (Cheng and Towle 2017).

This evaluation also provided an example of a sociocultural learning environment, which complemented the theoretical aspects of the children's palliative care module. It enabled students to see 'patients' as 'people' and increased their understanding of the implications and effects of healthcare intervention choices. This has positive implications for a more collaborative and person-centred practice where nurses can provide high-quality care and support with skill, compassion and imagination (Atwal et al 2018).

Limitations

The participants chose to take part in the children's palliative care module, which could have meant that they had a predisposition to find the workshop valuable. The evaluation forms were completed anonymously at the end of the workshop and returned to the facilitators. The questions asked were relatively simple and it is acknowledged that the evaluation form could be improved to gather more detailed information.

Conclusion

This small-scale evaluation has revealed a model of service user-facilitated learning which offers a way of understanding how meaningful and high-level involvement of service users in nurse education can promote learning. This was achieved through the creation of a safe space that enabled a shift in perspective, which could then be applied to enhance practice. The experience of the participants demonstrated the importance of developing meaningful partnership between academics and service users to achieve authentic, person-centred healthcare education.

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Why you should read this article:

- To read about a study of adolescents' use of social media as a coping strategy during COVID-19
- To increase your knowledge of types of coping mechanisms used by adolescents during challenging situations
- To enhance your understanding of the positive and negative effects of using social media as a coping mechanism

Stress and loneliness: exploring adolescents' use of social media as a coping strategy during COVID-19

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Abstract

Background During the coronavirus disease 2019 (COVID-19) pandemic, adolescents used various coping strategies to manage stress and loneliness. One such strategy was to engage in active coping, social relations coping and humour coping via social media. Such coping strategies can be helpful but can also reinforce stress and loneliness.

Aim To explore adolescents' use of social media to manage stress and loneliness at a time of restricted social contacts due to the COVID-19 pandemic, including potential differences between adolescents according to gender, age, area of residence and extent of social media use.

Method A cross-sectional design and an online questionnaire were used to survey a convenience sample of adolescents aged between 12 and 18 years in Jordan. Three data collection tools were used – the modified Brief Coping Scale, the six-item Revised UCLA Loneliness Scale and the Perceived Stress Scale.

Results A total of 770 adolescents participated, half of whom were using social media more than before the pandemic. Increased use of active coping, social relations coping and humour coping was associated with decreases in stress and loneliness. Active coping contributed the most to reducing levels of stress while social relations coping contributed the most to reducing levels of loneliness. Younger participants made more use of active coping and humour coping than older participants.

Conclusion Social media use can be a positive coping strategy for adolescents to manage stress and loneliness during a crisis such as the COVID-19 pandemic.

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Keywords

adolescents, anxiety, child and adolescent mental health, child health, communication, COVID-19, mental health, professional, social media, stress

Background

During the coronavirus disease 2019 (COVID-19) pandemic, many schools were closed and most activities for children and young people that usually take place outside the home and in groups were restricted. The consequent social isolation increased the incidence of mental health issues in this group (Brooks et al 2020, Xiang et al 2020, Al Omari et al 2021, Cauberghe et al 2021, Zainel et al 2021). Adolescence is already a time of life associated with feelings of social

isolation (Uccella et al 2021) and a higher risk of mental health issues, so a major crisis situation such as the COVID-19 pandemic would be expected to increase the severity of such issues and the number of adolescents who experience them (Laursen and Hartl 2013, Al Omari et al 2021). Indeed, the pandemic has been linked to negative consequences on the mental health of children and young people (Morgül et al 2020, Meherali et al 2021).

Adolescents coped in various ways with managing stress, anxiety and loneliness, including making substantial use of social media platforms (Barron Millar et al 2021). However, such coping strategies can reinforce stress, anxiety and loneliness in the long term (Olatunji et al 2011); Lisitsa et al (2020), for example, demonstrated a relationship between stress and substantial use of social media during the pandemic. Conversely, some adolescents may have found using social media helpful for managing stress and loneliness, so it is important to determine how this can be used as an effective coping strategy during a crisis situation such as the COVID-19 pandemic (Zainel et al 2021).

Many coping mechanisms used by people faced with challenging situations have been identified, researched and described in the literature, including active coping or problem-focused coping (Lazarus 2006), social relations coping (Sarason and Sarason 1985) and humour coping (Nezlek and Derks 2001). Cauberghe et al (2021) explored how adolescents used three coping strategies – active coping, social relations coping and humour coping – via social media to manage the challenges created by the COVID-19 pandemic. The participants appeared to use social media to source information about the pandemic (active coping), stay in touch with their friends and break social isolation (social relations coping) and/or watch and share videos, jokes and memes (humour coping).

Aim

The aim of the study was to explore adolescents' use of social media to manage stress and loneliness at a time of restricted social contacts due to the COVID-19 pandemic, including potential differences between adolescents according to gender, age, area of residence and extent of social media use. The research questions were:

- What is the relationship between adolescents' gender, age, area of residence and extent of social media use on the one hand, and the combination of active coping, social relations coping and humour coping on the other hand?
- Does the combination of the three coping strategies predict adolescents' levels of stress and loneliness and, if so, how well?

Method

Sampling and data collection

A cross-sectional design was used and an online questionnaire was developed to survey a convenience sample of adolescents aged between 12 years and 18 years in Jordan. Data collection took place between 2 April and 25 August 2020. Three methods were used to disseminate the survey link:

- School administrators in 11 schools (five in urban areas and six in rural areas of north and central Jordan) sent the survey link to all students on the students' social media accounts and/or emails.
- Social workers and counsellors working for four organisations providing psychological, academic and social support to young people in Jordan shared the survey link with parents on WhatsApp.
- The survey link was posted on publicly visible posts on Facebook, whose users could share it with others.

The total number of potential participants was not known so the overall response rate could not be calculated. Of the 862 responses received by the end of the data collection period, 770 were complete, giving a complete response rate of 89%. Complete response rates obtained in online surveys have been shown to range from 20% to 56% (Naslund et al 2019).

Data collection tools

Three data collection tools were used, which were translated from English into Arabic and back into English by three authorised translators to ensure their accuracy of meaning.

Brief Coping Scale

The Brief Coping Scale (BCS) was originally developed by Yang (2016) to measure how adolescents use social media to cope with stress and adjustment problems. Cauberghe et al (2021) modified the BCS to measure adolescents' use of three coping strategies – active coping, social relations coping and humour coping – via social media to manage the challenges created by the COVID-19 pandemic. The modified BCS was used in the present study and contains nine items: four on active coping, three on social relations coping and two on humour coping. Answers are given on a five-point Likert-type scale ranging from 1 ('I don't use') to 5 ('I always use'). Higher scores reflect a higher

use of the three coping strategies via social media. The inter-rater validity of the modified BCS was checked by a panel of experts and its validity calculated through confirmatory factor analysis. Its reliability was checked through test-retest reliability (0.87) and internal consistency (Cronbach's alpha=0.90).

Perceived Stress Scale

The Perceived Stress Scale (PSS) was developed by Cohen et al (1983) to measure perceived stress. It contains ten items assessed on a five-point Likert scale ranging from 0 ('never') to 4 ('always'). Scores between 0 and 13 indicate low levels of stress, scores between 14 and 26 indicate moderate levels of stress and scores between 27 and 40 indicate high levels of stress (Cohen et al 1983, Cohen and Janicki-Deverts 2012). The PSS was used in the present study to assess participants' levels of perceived stress. The inter-rater validity was checked by a panel of experts and its reliability was checked through test-retest reliability (0.89) and internal consistency (Cronbach's alpha=0.80).

Six-item Revised UCLA Loneliness Scale

The UCLA Loneliness Scale was originally developed by Russell et al (1978) as a 20-item scale and has since been revised several times, including by Russell et al (1980). Wongpakaran et al (2020) developed and validated a shorter version of the Revised UCLA Loneliness Scale containing six items (R-ULS-6). Answers are given on a four-point Likert-type scale ranging from 1 ('never') to 4 ('always') and higher scores reflect greater loneliness. Wongpakaran et al's (2020) R-ULS-6 was used in the present study to assess participants' levels of loneliness. Inter-rater validity was checked by a panel of experts and reliability was checked through test-retest reliability (0.85) and internal consistency (Cronbach's alpha=0.83).

Data analysis

Multivariate analysis of variance (MANOVA) and multiple regression analysis were used to answer the two research questions. The result of Box's M test, which is used to test for equivalence of covariance matrices, was not significant, which meant that the assumption of homogeneity of covariance matrices between the three coping strategies for the categories of gender, age, area of residence and extent of social media use was met. The assumption of homogeneity of error variances of each coping strategy for the different variables was also correct, since Levene's test was not significant for any of the strategies. The assumptions of univariate and multivariate normality were checked and found to be correct. Finally, correlation coefficients between the three coping strategies ranged between 0.38 (between social relations coping and humour coping) and 0.55 (between active coping and social relations coping), which indicated the potential absence of multicollinearity between the three coping strategies.

Ethical considerations

The administrative approval process at the Hashemite University in Jordan involves submitting the research proposal to the head of department, who checks its methodological and ethical components in collaboration with colleagues. In this case, the head of department granted approval for the study. The study was conducted in line with the recommendations of the 1989 Helsinki Declaration for physicians conducting biomedical research involving human subjects (World Medical Association 1989). Participants were informed that their involvement was voluntary, that they could choose not to answer questions and that they could withdraw from the study at any time. No identifying data were collected, which ensured participants' anonymity.

Results

A total of 770 adolescents participated in the study. Table 1 shows the demographic characteristics of the study sample.

To assess whether there were differences in the three coping strategies as a function of gender, age, area of residence and extent

Table 1. Demographic characteristics of the study sample (*n*=770)

Gender	Female	454 (59%)
	Male	316 (41%)
Age	12-14 years	211 (27%)
	14-16 years	390 (51%)
	16-18 years	169 (22%)
Area of residence	Rural area	461 (60%)
	Urban area	309 (40%)
Extent of social media use	Less than before the pandemic	109 (14%)
	Same as before the pandemic	272 (35%)
	More than before the pandemic	389 (51%)

Implications for practice

- Social media use can be a positive coping strategy but there is a risk that it may reinforce stress and loneliness, so young people would benefit from guidance on how to use it effectively
- Mental health nurses and school nurses could organise workshops for young people on optimal use of social media to manage mental health issues
- Young people could be shown how to use active coping, social relations coping and humour coping via social media for managing stress and loneliness, particularly in a crisis situation

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of social media use, the mean and standard deviation for each coping strategy was calculated as a function of each independent variable – see Table 2.

The only statistically significant multivariate effect on the three coping strategies was age (Wilks' lambda=0.980, F (6, 1522)=2.58, P<0.05), as shown in Table 3. This means that the linear combination of the three coping strategies differed for each of the three age ranges of participants.

Table 2. Mean and standard deviation for each coping strategy* as a function of gender, age, area of residence and extent of social media use

Independent variable		Number	Mean (standard deviation)		
			Active coping	Social relations coping	Humour coping
Gender	Female	454	3.14 (0.99)	3.05 (0.91)	2.96 (1.25)
	Male	316	3.10 (0.93)	3.08 (0.95)	3.06 (1.28)
Age	12-14 years	211	3.32 (0.95)	3.15 (0.90)	3.21 (1.22)
	14-16 years	390	3.07 (0.99)	3.04 (0.93)	2.95 (1.28)
	16-18 years	169	2.99 (0.91)	3.00 (0.95)	2.86 (1.24)
Area of residence	Rural area	461	3.12 (0.99)	3.06 (0.93)	3.04 (1.25)
	Urban area	309	3.13 (0.94)	3.06 (0.92)	2.94 (1.29)
Extent of social media use	Less than before the pandemic	109	3.15 (0.95)	3.09 (0.90)	3.17 (1.23)
	Same as before the pandemic	272	3.06 (1.01)	3.03 (0.91)	2.92 (1.28)
	More than before the pandemic	389	3.16 (0.95)	3.07 (0.95)	3.01 (1.26)

* As measured on the modified Brief Coping Scale (Cauberghe et al 2021)

Table 3. Multivariate effects of gender, age, area of residence and extent of social media use on the three coping strategies*

	Wilks' lambda	F (variance ratio)	Hypothesis df (degree of freedom)	Error df (degree of freedom)	Sig (significance probability)
Gender	0.993	1.72	3.000	761.00	0.161
Age	0.980	2.58	6.000	1522.00	0.017†
Area of residence	0.996	1.04	3.000	761.00	0.380
Extent of social media use	0.994	0.82	6.000	1522.79	0.551

*Measured on the modified Brief Coping Scale (Cauberghe et al 2021); †Probability value (P)<0.05

Table 4 shows the results of the subsequent analysis of variance (ANOVA). The only univariate effect that was statistically significant was age and the univariate effect of age was only statistically significant for two of the three coping strategies – active coping (F (2, 763)=6.29, P<0.01) and humour coping (F (2, 763)=5.02, P<0.01). Post-hoc comparisons between the univariate effects of each of the three age ranges on participants' active coping and humour coping strategies using Tukey's test showed those in the younger age range (12-14 years) used active coping and humour coping more than those in the older age ranges (14-16 years and 16-18 years). Tukey's test is used in post hoc comparisons after an ANOVA has shown that significant differences exist between more than two means; the test is computed through a pairwise comparisons of all means.

Multiple linear regression analysis was conducted to determine whether the combination of active coping, social relations coping and humour coping would predict participants' levels of stress and loneliness. Table 5 shows the mean, standard deviation and intercorrelation between stress, loneliness and the three coping strategies. The three coping strategies were negatively correlated with stress and loneliness, which means that the increased use of these strategies was associated with a significant decrease in levels of stress and loneliness among adolescents. The coefficients of correlation were higher for stress than for loneliness.

Table 6 shows that the combination of the three coping strategies significantly predicted participants' levels of stress (F (3, 766)=328.59, P<0.001) and loneliness (F (3, 766)=72.39, P<0.001), with all three coping strategies significantly contributing to the prediction. For predicting levels of stress, the adjusted R^2 value was 0.561, indicating that 56% of the variance in stress levels was explained by the model. For predicting levels of loneliness, the adjusted R^2 value was 0.22, indicating that 22% of the variance in loneliness levels was explained by the model. The beta weights shown in Table 6 suggest that:

- Increasing use of the three coping strategies resulted in decreased levels of stress, with active coping contributing the most to the decrease followed by humour coping and social relations coping.
- Increasing use of the three coping strategies resulted in decreased levels of loneliness, with social relations coping contributing the most to the decrease followed by active coping and humour coping.

Discussion

The aim of the study was to explore adolescents' use of social media to manage stress and loneliness at a time of restricted social contacts due to the COVID-19 pandemic, including potential differences between adolescents according to gender, age, area of residence and extent of social media use.

There were no statistically significant differences in the three coping strategies according to gender, area of residence and extent of social media use, but participants appeared to differ in their use of these strategies according to age. Other studies have shown that crisis situations can have different effects on adolescents according to age (Damra 2013, Barron Millar et al 2021, Uccella et al 2021). Younger cohorts tend to perceive a crisis situation as more threatening than older cohorts and may therefore resort to different ways of coping. This could explain why younger participants in the present study used active coping and humour coping more than older participants.

The results showed that increased use of the three coping strategies was associated with statistically significant decreases in levels of stress and loneliness, the effect being stronger for stress than for loneliness; 56% of the variance in stress levels and 22% of the variance in loneliness levels were predicted by use of the three coping strategies. Active coping contributed the most to reducing stress while social relations coping contributed the most to reducing loneliness. Cauberghe et al (2021) found that, to some degree, adolescents' use of social media to manage the challenges created by the COVID-19 pandemic relieved their distress and anxiety, increased their happiness and reduced their loneliness. Adolescents who engage in positive coping strategies via social media may have more positive relationships with others, feel less uncertainty, be less burdened and be more able to lighten their own and their peers' mood by using humour.

Humour can be a healing medium (Martin 2002) and is used extensively for building connections, promoting positive interactions, facilitating self-disclosure and decreasing stress and conflict (Martin et al 2003). Humour coping via social media, notably through sharing videos, memes and jokes, was used as a coping strategy during the COVID-19 pandemic by people in general (Chiodo et al 2020) and adolescents in particular (Kodak and Oduor 2020, Sebba-Elran 2021). Kodak and Oduor

Table 4. Univariate effects of gender, area of residence, age and extent of social media use on the three coping strategies*

	Dependent variable	SS (sum of squares)	df (degree of freedom)	MS (mean square)	*F* (variance ratio)	Sig (significance probability)
Gender	Active coping	0.010	1	0.010	0.011	0.918
	Social relations coping	0.607	1	0.607	0.705	0.401
	Humour coping	5.269	1	5.269	3.348	0.068
Age	Active coping	11.787	2	5.894	6.292	0.002†
	Social relations coping	2.845	2	1.422	1.653	0.192
	Humour coping	15.804	2	7.902	5.021	0.007†
Area of residence	Active coping	0.003	1	0.003	0.004	0.953
	Social relations coping	0.016	1	0.016	0.019	0.891
	Humour coping	3.871	1	3.871	2.460	0.117
Extent of social media use	Active coping	1.693	2	0.847	0.904	0.405
	Social relations coping	0.405	2	0.203	0.236	0.790
	Humour coping	5.046	2	2.523	1.603	0.202
Error	Active coping	714.680	763	0.937		
	Social relations coping	656.392	763	0.860		
	Humour coping	1200.755	763	1.574		

*Measured on the modified Brief Coping Scale (Cauberghe et al 2021); †Probability value (*P*)<0.01

Table 5. Mean, standard deviation and intercorrelation between stress, loneliness and the three coping strategies*

		Mean	Standard deviation	Active coping	Social relations coping	Humour coping
Stress		1.99	0.77	*r*=-0.71†	*r*=-0.49‡	*r*=-0.55†
Loneliness		2.40	0.72	*r*=-0.41†	*r*=-0.41‡	*r*=-0.30†
Predictor variable	Active coping	3.12	0.97	–	*r*=0.55‡	*r*=0.49†
	Social relations coping	3.06	0.93	*r*=-0.49†	–	*r*=0.38†
	Humour coping	3.00	1.26	*r*=0.49†	*r*=0.38†	–

*Stress as measured on the Perceived Stress Scale (Cohen et al 1983); loneliness as measured on the Revised UCLA Loneliness Scale (Wongpakaran et al 2020); coping strategies as measured on the modified Brief Coping Scale (Cauberghe et al 2021); *r* = coefficient of correlation; †Probability value (*P*)<0.01; ‡Probability value (*P*)<0.001

(2020) found that the use of humour coping by adolescents during the pandemic could decrease tension, create bonds, reinforce resilience to stress, distract from worries and normalise their experiences. Sebba-Elran (2021) showed that it could regulate anxiety, reduce stress and fear, resolve conflict and help maintain communication with others.

Zillmann's (1988) mood management theory suggests that the consumption of messages – particularly entertaining messages – can change a person's prevailing mood and that people select specific messages for consumption as a way of regulating their mood. This may explain why adolescents use social media to manage their mental health issues, regulate their emotions and reduce their loneliness (Greenwood and Long 2009, Kim et al 2011). In the present study, approximately half of participants (n=389, 51%) used social media more than before the pandemic, which confirms to some extent the hypothesis that social media use is prompted by a need to self-regulate negative emotions. In times of crisis, people subconsciously use certain social media applications or outlets to regulate their emotional state and achieve a more positive mood (Eriksson 2018).

The results confirm that adolescents use social media as a means of coping with stress and loneliness. They are consistent with the results of other studies (Barron Millar et al 2021, Cauberghe et al 2021) whose participants made extensive use of social media to cope with the social isolation created by the COVID-19 pandemic. Stress and loneliness have been shown to drive adolescents to use social media as a positive coping strategy (Reinecke and Oliver 2016, Aalbers et al 2019). However, the positive effects of social media use on participants' mental health in the present study contrast with the negative effects during times of crisis demonstrated, for example, by Kim et al (2011), Radovic et al (2017) and Chao et al (2020) – one of the risks being that people's use of social media is a passive rather than active way of engaging with others and seeking social support.

Ng et al (2012) noted that the increased use of the internet by adolescents could be viewed as an avoidance mechanism, but for Radovic et al (2017) it could be seen as a positive coping mechanism. Adolescents appear to have conflicting perceptions of their social media use. Radovic et al (2017) found that some adolescents who saw themselves as highly worried or lonely reported that using social media made them feel more relaxed, brave and popular, but others felt it made them feel worse about themselves and less confident; social media use can, therefore, reinforce adolescents' social isolation (Kim et al 2011, Radovic et al 2017, Chao et al 2020). Aathira and Geetha (2020) found that most adolescents they surveyed were aware of the role of social media during the pandemic and that it could spread correct information and misinformation.

Future studies could examine how children and young people with mental health issues use social media to cope with the emotional, psychological and social consequences of crisis situations. Young people use a variety of social media platforms, so it could be useful to explore how their use of different coping strategies correlates with their use of different platforms.

Table 6. Multiple regression analysis showing how the combination of the three coping strategies predicted stress and loneliness*

Variable	B (unstandardised beta)		SEB (standard error for the unstandardised beta)		β (standardised beta)	
	Stress	Loneliness	Stress	Loneliness	Stress	Loneliness
Active coping	−0.418	−0.172	0.024	0.030	−0.533†	−0.233†
Social relations coping	−0.086	−0.189	0.024	0.030	−0.104†	−0.243†
Humour coping	−0.149	−0.052	0.017	0.021	−0.245†	−0.091‡
Constant	4.012	3.672	0.071	0.089	–	–
	Stress R^2=0.561; F (3, 766)=328.59; P<0.001					
	Loneliness R^2=0.22; F (3, 766)=72.39; P<0.001					

*Stress as measured on the Perceived Stress Scale (Cohen et al 1983); loneliness as measured on the Revised UCLA Loneliness Scale (Wongpakaran et al 2020); coping strategies as measured on the modified Brief Coping Scale (Cauberghe et al 2021); R^2 = coefficient of determination; F=variance ratio; P=probability value; † P<0.001; ‡ P<0.05

Limitations

The study was conducted with a convenience sample of young people aged 12 to 18 years in Jordan, which limits the generalisability of the results. No information was collected about participants' mental health status, for example whether they had depression or experienced anxiety. Responses may have been biased because those who chose to participate could have been active social media users and/or particularly interested in using social media as a coping strategy. However, it is unlikely that participants would have been dishonest about their

use of social media, since they received no compensation for participating.

Data collection took place after the height of the COVID-19 pandemic in Jordan, so by then participants would have become more used to the pandemic and the intensity of their emotions could have decreased.

Conclusion

Most of the adolescents in this study made more use of social media during the pandemic than before it. Participants engaged in three types of coping strategies – active coping, social relations coping and humour coping – via social media and this was associated with decreases in stress and loneliness, the effect being stronger for stress than for loneliness. The study therefore adds to the evidence that the use of social media can be a positive coping method for adolescents to manage stress and loneliness in a crisis situation.

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PEER-REVIEWED

Why you should read this article:

- To enhance your knowledge of the different types and causes of acquired brain injuries (ABIs) in infants, children and young people
- To increase your understanding of the pathophysiology of ABIs and associated complications
- To contribute towards revalidation as part of your 35 hours of CPD (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Neurological observations in infants, children and young people: part one

Kelvin McMillan, Hannah Shaw, Alice Hemesley et al

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Abstract

Caring for infants, children and young people with an acquired brain injury (ABI) can be challenging due to their developing brain and reliance on parents and caregivers. It is essential that children's nurses are able to perform effective neurological observations, because these can identify deterioration and inform the management of patients with an ABI. This is the first of two articles that aim to encourage accuracy and consistency when undertaking neurological observations in infants, children and young people with an ABI to optimise their care. This first article details the pathophysiology, types and causes of ABIs and explains the potential complications that can occur following such injuries.

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Keywords

child health, clinical, observations, neurology, nursing care, patient assessment, patients, professional

Aims and intended learning outcomes

The aim of these two articles on neurological observations in infants, children and young people is to explore the risks and complications associated with acquired brain injuries (ABIs) and to support children's nurses to undertake consistent and accurate neurological observations of patients at risk of deterioration. This first article aims to explain why infants, children and young people are vulnerable to ABIs and to outline the pathophysiology and effects of ABIs in children and young people. The second article will explain the elements of a neurological assessment in detail.

After reading this article and completing the time out activities you should be able to:

- Explain why infants, children and young people are vulnerable to ABIs.
- Outline various types of ABIs and mechanisms of injuries.
- Understand the pathophysiology of ABIs, including increased intracranial pressure and the Monro-Kellie doctrine.
- Discuss the effects of increased intracranial pressure on children and young people, including brain herniation.

Introduction

Headway (2023a) defines ABI as an injury to the brain since the point of birth. ABIs can have traumatic or non-traumatic causes, but do not include injuries to the brain that occur during fetal development. Traumatic brain

injuries (TBIs) are the most common type of ABI and are defined as any alteration to brain function or pathology due to an external force. Common causes of TBIs include road traffic accidents, falls, sports-related injuries and assault, including child abuse and shaken baby syndrome (Children's Trust 2023a).

ABIs can also be caused by internal pathological changes altering neurology, such as metabolic changes or internal masses or lesions that develop over time. Common causes of such internal pathological changes include (Children's Trust 2023b):

- Infections such as meningitis.
- Hypertension.
- Status epilepticus.
- Brain tumours.
- Reduced cerebral blood flow caused by underlying conditions such as cardiovascular disease.
- Toxins.
- Strokes.

The incidence of ABI varies depending on the cause. According to Headway (2023b), in 2019-2020 there were around 357,000 hospital admissions in the UK related to ABI in all ages. However, determining accurate rates of ABIs in children and young people can be challenging due to differences in the interpretation of what is classified as an ABI. According to the latest available UK statistics, there were approximately 35,000 hospital episodes in 2012-2013 involving children and young people with an ABI (Trefan et al 2016).

Understanding each patient's underlying health conditions and any complications resulting from preventive or therapeutic treatments is crucial, especially since any patient with an ABI could be vulnerable to neurological deterioration. For example, patients with conditions related to impaired detoxification, metabolic and/or excretion ability – such as those experiencing liver or/and renal failure or those with an underlying metabolic disorder – are at increased risk of blood-brain barrier interruption due to increasing toxicity or altered blood pH (Cui et al 2013). Similarly, patients with cardiorespiratory conditions may experience reduced cerebral perfusion (Zhu et al 2020).

TIME OUT 1

It is important for children's nurses to have adequate knowledge of the nervous system so they can understand the pathophysiological mechanisms that may result from an ABI. Refresh your knowledge of the nervous system by accessing the following resource: nurseslabs.com/nervous-system

Acquired brain injury in children and young people

Most ABIs in children are mild and are often related to falls. The ongoing development of the skull, face, brain and neck muscles can increase the susceptibility of children to distinct types of head injuries that are often not associated with adults (Araki et al 2017). For example, in relation to the size of a child's body, the head is heavy and large and rests on a neck that is not well supported due to weak muscles and ligaments, so head and cervical spine injuries may easily occur. Children's greater head-to-body weight ratio and weaker neck musculature may also lead to a greater likelihood of acceleration-deceleration injury (where the brain tissue moves in the opposite direction to the impact) and a higher vulnerability to shearing forces within the brain (Hung 2020). Additionally, due to the heavy weight of the head compared with the body, young children are much more likely to fall headfirst than older children and adults and therefore experience ABIs via this mechanism (Joyce et al 2022).

In addition, scalp and facial veins are more prominent in children than in adults, meaning there is an increased risk of potentially fatal blood loss because even a small reduction of blood volume may result in haemorrhagic shock, especially in neonates, infants and toddlers (Clarke and Sokoloff 1999). Haemorrhagic shock may occur without external bleeding, so might not be an obvious initial consideration when a child or infant presents to the clinical setting, thus demonstrating the importance of undertaking neurological assessment, particularly in TBIs.

Over the past 30 years, increasing neuroimaging research has demonstrated that during adolescence the brain remains in a growth and development period, contrary to the longstanding belief that the brain has fully matured by puberty (Arain et al 2013). The prefrontal cortex – responsible for planning, working memory and impulse control – is one of the last areas of the brain to mature, and may not be fully developed until the age of 25 years (Sowell et al 2001). This suggests that there is a link between early age and a lack of maturity in relation to judgement, impulse control and risk-taking, thus increasing the risk of exposure to ABIs. Therefore, compared with adults, children and young people are more likely to act on impulse and not consider the risks associated with their actions, although this peaks during adolescence (Albert et al 2013).

Key points

- It is essential that children's nurses understand the pathophysiology of acquired brain injuries (ABIs) to support early recognition of neurological deterioration in children and young people
- The presentation of a child or young person with an ABI can depend on the primary mechanism of injury, the location and distribution of the injury, and whether secondary complications occur
- The outcome of the primary mechanism of an ABI cannot be improved but preventive measures such as treating blood loss can help avoid further complications
- ABIs can cause cellular, metabolic and biochemical changes to the brain, which can differ depending on the primary and/or secondary injury

Online archive
For related information, visit **nursingchildrenandyoungpeople.co.uk** and search using the keywords

Furthermore, infants and younger children are at an increased risk of infection because their immune systems are not yet fully developed (Maródi 2006). Although certain protective antibodies are passed from the mother to the fetus via the placenta, the levels of antibodies in the fetus's blood are insufficient to fight some infections (Palmeira et al 2012). Examples of such infections include bacterial meningitis, which can lead to sepsis and subsequently brain injury, and viral infections such as *cytomegalovirus*, Epstein-Barr, chicken pox or shingles, which can also cause significant harm to the brain through encephalitis (swelling or irritation of the brain) (Thompson et al 2011).

One challenge when conducting a neurological assessment of a child suspected to have an ABI is that they may appear well at the time, but may develop cognitive and behavioural issues as they become older (Varshneya et al 2019). Adults often experience the effects of an ABI immediately, but in infants and children the effects may take much longer to occur, with the injury becoming increasingly obvious as it progresses. This is because children's brains continue to develop until late adolescence, so it is sometimes only when the brain is fully developed that the full extent of a brain injury can be known.

It can also be challenging for parents and caregivers to identify if their child requires medical attention and for GPs to make decisions about referrals, particularly in the early stages of an ABI. For example, in early meningitis, infants may present with vomiting, being off their feeds, pyrexia and irritability – symptoms which are also suggestive of a variety of common childhood bacterial and viral illnesses (Kim 2010). Therefore, early identification of meningitis may not be possible. This demonstrates the importance of a thorough neurological assessment, as well as neuroimaging where appropriate, to reduce the risk of missing an ABI. Further information about the elements of such an assessment in infants, children and young people will be provided in the second article.

Table 1. Main differences in clinical presentation depending on the location of an acquired brain injury

Location in the brain	Clinical presentation
Frontal lobe	» Behavioural changes or issues such as agitation, aggression and reduced inhibitions » Mood changes such as depression » Loss of strength in the muscles » Aphasia (reduced or absent understanding of written or spoken language) » Reduced voluntary muscle movements, such as walking or holding a pencil » Short-term memory loss
Temporal lobe	» Short-term memory loss » Hearing loss » Difficulty forming words or sentences » Loss of sense of smell » Aphasia
Parietal lobe	» Reduced or absent sensation, sometimes down one half of the body » Dyscalculia (difficulty understanding numbers) » Difficulty reading
Occipital lobe	» Visual impairments » Difficulty seeing or identifying colours » Difficulty recognising or interpreting familiar objects
Cerebellum	» Cerebellar ataxia (jerky or uncoordinated movements) » Imbalance » Visual impairments » Slurred speech

(Javed and Lui 2022)

Mechanisms of injury

ABIs can be classed as either focal or diffuse and are caused by either penetrating (open) injuries or non-penetrating (closed) injuries. Focal ABIs occur in a specific location and result from a direct force, causing compression of brain tissue under the skull or acceleration-deceleration injury. Diffuse ABIs occur over a widespread area of the brain, resulting in diffuse axonal injury, ischaemia and oedema, and may be caused by (Cui et al 2013, Headway 2023a):

- Hypoxia – interruption to cerebral blood flow, prolonged seizure activity or reduced oxygenation.
- Infection – for example meningitis.
- Toxins – for example overdose of paracetamol.
- Metabolic alterations – for example diabetic ketoacidosis, kernicterus or hepatic encephalopathy.

The presentation of a child or young person with an ABI can depend on the primary mechanism of injury, the location and distribution of the injury and whether secondary complications occur. Table 1 details the main differences in clinical presentation depending on the location of an ABI.

Mechanical damage to brain tissue and blood vessels can result from shearing or tearing forces, with children being more vulnerable to these forces due to their limited neck control and larger heads compared with body size (Araki et al 2017). Table 2 summarises the common types and causes of TBIs across the lifespan.

CPD CONTINUING PROFESSIONAL DEVELOPMENT

TIME OUT 2

Imagine that you need to communicate with the parent of a child who has experienced an ABI. The parent appears highly anxious and is seeking further information about their child's injury. How would you manage their anxiety and explain concepts such as intracranial pressure and cerebral oedema to them?

TIME OUT 3

What are the signs and symptoms of increased intracranial pressure, and how do these vary depending on the age of a child? You may wish to access the following resource for further information: **www.nationwidechildrens.org/conditions/increased-intracranial-pressure**

Complications of acquired brain injury

The outcome of the primary mechanism of an ABI cannot be improved, whether it is a focal or diffuse injury. However, preventive measures such as treating blood loss can avoid further complications (Mckee and Daneshvar 2015). ABIs can cause cellular, metabolic and biochemical changes to the brain which can differ depending on the primary and/or secondary injury. This can cause disruption in the integrity of the blood-brain barrier, which is normally a tight junction of cells that prevents anything harmful from entering the delicate brain cells. ABIs can cause the following complications (Zimmerman et al 2021, Royal Children's Hospital Melbourne 2023):

- An inflammatory response to pathogens, tissue injury or allergens. If inflammation is prolonged, vascular leakage causes an influx of proteins that increases osmotic pressure in the brain, leading to cerebral oedema and therefore increased intracranial pressure. Children are more vulnerable to diffuse cerebral oedema because they have a higher cerebral blood flow than young people and adults, influenced by having a higher cardiac output. However, the underlying pathophysiology for this remains unclear.
- Pathogen transmission into the meninges and parenchyma due to inflammation. Infants and young children have an immature immune system so are more vulnerable to illnesses such as meningitis and encephalitis due to a delayed white blood cell response. Pathogens that cause infections of the brain include group B *Streptococcus*, *Escherichia coli*, herpes simplex virus and *Mycobacterium tuberculosis*.
- Injury to neurons that can cause glutamate, considered the primary excitatory neurotransmitter in the nervous system, to enter extracellular spaces, which triggers an influx of sodium and calcium ions into the neurons. Due to oxidative stress and a large influx of calcium ions resulting from glutamate disruption, the mitochondria of the neurons will fail to produce adenosine triphosphate (a source of energy for cells), which can result in neuron death and necrosis.

Intracranial pressure

The skull is a fixed cranial vault that provides protection and support for the cranial contents. Within the skull, the intracranial space is occupied principally by brain matter, which constitutes 80% to 90% of the volume. Cerebrospinal fluid (CSF) occupies 6-10% and blood occupies the least amount

Table 2. Common types and causes of traumatic brain injuries (TBIs) across the lifespan

Age group	Common types and causes of TBIs
Neonates	» Intracranial, subgaleal or cephalic haemorrhage » Abusive head trauma, for example due to non-accidental injury or shaken baby syndrome » During childbirth vaginal deliveries may lead to head compression or trauma resulting from passage through the birth canal or from the use of obstetric instruments to assist with the birthing process
Infants	» Abusive head trauma – this is the most common cause of TBI-related hospitalisation and death in infants. It is important to be aware that this is a safeguarding concern » Accidents » Skull fractures » Subdural or extradural haematoma » Infants are reliant on their parents or caregivers, so TBIs in this age group may occur if they are dropped from their caregiver's arms or fall from furniture or as a result of inappropriate supervision or childcare practices » Infants have a large head-to-body ratio and their head is unsupported by weak neck muscles
Toddlers and school-age children	» Accidents » Falls, for example from heights or down stairs, are the most common cause of head injury in this age group » Pedestrian injury, for example being hit by a car » Skull fractures » Cerebral oedema » At this age, the child's motor ability increases but their spatial awareness and knowledge of consequences remains limited, which can lead to increased risk of injury
Adolescents	» Sports-related head injuries » Concussion » Falls » Blunt force trauma » May occur due to not wearing protective equipment such as helmets » This age group will have more independence and less adult supervision than younger children » Adolescents may experience peer pressure and reduced resistance to peer influence, and are often prone to risk-taking

(Pinto et al 2012, Albert et al 2013, Burrows et al 2015, Araki et al 2017)

of intracranial volume at 4-10%. This is referred to as the Monro-Kellie doctrine, which states that the volume of all three components together within the intracranial space is constant.

Up to the age of two years, the skull is separated by fibrous bands called sutures, which is important as the brain is rapidly developing and growing during this time. From the age of two years, the skull plates fuse together leaving no gaps (Stanford Medicine Children's Health 2022). Figure 1 shows the suture sites in an infant's skull.

Any increase in one of these components should cause a decrease in one or both of the remaining components (Wilson 2016). For a child under the age of two years, increased intracranial pressure can increase the head circumference as the skull plates are not yet fixed together. Therefore, children under the age of two years can compensate further for increased intracranial volume compared with older children and adults.

Compensation of intracranial volume can be achieved up to an intracranial pressure of 20mmHg in children, young people and adults (Czosnyka and Pickard 2004). Intracranial hypertension occurs when this pressure is above 20mmHg, which increases the risk of reduced cerebral perfusion and may lead to focal or/and global ischaemia. Figure 2 shows the effects of changes in the intracranial space due to a mass or lesion.

Signs and symptoms that can indicate increased intracranial pressure include (Adoni and McNett 2007, Paul et al 2013):

- Nausea and vomiting – this can be projectile vomiting.
- Altered mental state – caused by increased intracranial pressure that results in brain ischaemia to particular parts of the brain. Presentation can vary, for example a patient may present with confusion, disorientation, incoherent speech or slow responses to questions.
- Reduced arousal – it may be more challenging to stimulate patients and they may have slower voluntary responses.
- Unequal pupils (anisocoria) – caused by disruption to efferent neural pathways or compression to the third cranial nerve. It can also be an initial sign of brain herniation.
- Severe headaches – caused by compression of brain matter against the skull and reduction in CSF.
- Weakness in the arms and legs – increased intracranial pressure can interfere with motor coordination. It can also cause ataxia, resulting in balance issues, speech difficulties and reduced coordination.
- Behavioural changes – depending on where the mass or lesion is located, a patient may present with various behavioural changes, including aggression, irritability, unwillingness to eat and lethargy. In infants, high-pitched crying and not feeding are further examples of behaviour changes.
- Seizures – masses and lesions can interfere with neuron activity, which can increase the risk of seizures.
- In infants, a bulging fontanelle and increasing head circumference are signs of increased intracranial pressure.

Cerebral perfusion pressure

Normally, the brain can regulate blood flow through cerebral blood vessels by changing the cerebral vascular resistance via autoregulation. This requires a stable mean arterial pressure and intracranial pressure, which enables cerebral perfusion to be optimised to help maintain brain function (Armstead 2016). This is influenced by cerebral perfusion pressure, which is calculated using the following formula: mean arterial pressure + intracranial pressure = cerebral perfusion pressure.

When intracranial pressure increases because of an injury, or mean arterial pressure reduces, cerebral blood flow can be altered, thus reducing cerebral perfusion pressure.

Figure 1. Suture sites in an infant's skull

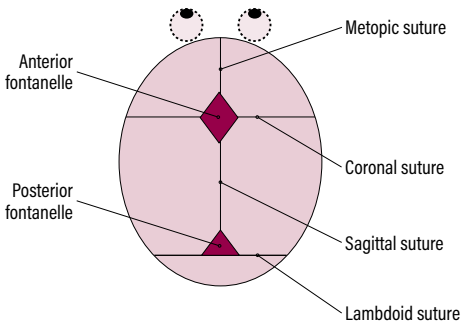
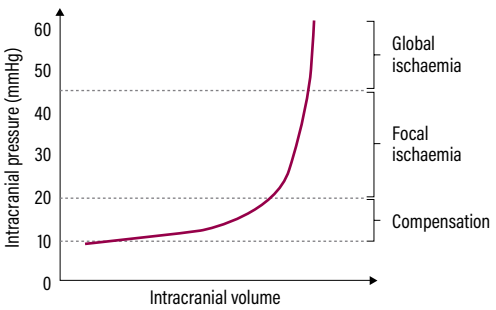


Figure 2. Effects of changes in the intracranial space due to a mass or lesion



This increases the risk of secondary injuries as patients are vulnerable to cerebral oedema, further neuronal death and brain herniation. Increased intracranial pressure and reduced cerebral perfusion pressure triggers a nervous system response called Cushing's reflex. This results in three main signs known as Cushing's triad: widening pulse pressure (a large difference between systolic blood pressure and diastolic blood pressure), bradycardia and irregular respirations (Dinallo and Waseem 2022).

Prevention of secondary injuries to the brain is a priority when managing patients with ABIs to reduce the risk of interrupted cerebral perfusion caused by increased intracranial pressure. Therefore, an understanding of neurological anatomy, physiology and assessments is vital for children's nurses to improve patient outcomes (National Institute for Health and Care Excellence 2014, 2019). Early identification of reduced cerebral perfusion using a thorough neurological assessment can lead to swifter medical intervention, which is essential to reduce the effects of secondary injury on the brain.

Cerebrospinal fluid leaks

ABIs can cause CSF leaks, which is one of the most common complications following a TBI (Oh et al 2017). Such a leak occurs when CSF escapes via a hole or tear in the dura mater (the outermost layer of the meninges). The dura mater may be injured or torn by a TBI or surgical procedures that involve the sinuses, brain or spine, or may be damaged by clinical procedures such as a lumbar puncture, spinal tap, spinal anaesthesia or myelogram (Carrau et al 2005, Severson et al 2021). In addition, spontaneous CSF leaks may occur due to increased intracranial pressure. For example, this may occur in patients with hydrocephalus, where an increasing volume of CSF builds up within the skull (Carrau et al 2005, Severson et al 2021). Intracranial pressure is directly affected by changes to CSF in the brain and spinal cord, which may occur because of changes in the production and/or absorption rate of CSF, or obstructed CSF flow in the ventricular system (Bothwell et al 2019).

An opening in the subarachnoid space, which lies between the membranous layers of the arachnoid mater and the pia mater and surrounds the brain and the spinal cord, can also lead to life-threatening central nervous system infections such as meningitis (Kaufman et al 1990). When assessing children and young people, diagnosis of CSF leaks and infections can be obscured by other injuries or symptoms, for example in patients with basilar skull fractures or those who have an extraventricular drain in place, which encourages a closed system for CSF drainage for assessment and monitoring purposes. Therefore, a thorough assessment that takes into account the typical symptoms of a CSF leak is required (Box 1).

Where there is an expanding intracranial mass or lesion, drainage of CSF and blood are the main methods of compensation to provide space. Figure 3 shows the relationship between intracranial volumes where there is an intracranial mass or lesion. CSF can move between the cranium and the spinal subarachnoid space, while cerebral autoregulation helps to maintain cerebral blood flow and therefore cerebral perfusion pressure. When this is exhausted, meaning that no more CSF can be displaced, the intracranial pressure begins to rise. Increased intracranial volume can then alter cerebral blood flow, which will consequently reduce cerebral perfusion pressure. This relates to the Monro-Kellie doctrine, as the volume of one or two components needs to reduce as compensation in a limited space.

Brain herniation

The brain contains inward dura mater folds that make up compartments within the intracranial space. This provides subdivisions of the brain, for example separating the right and left hemispheres of the brain. Each compartment is designed to provide structural support for the two central hemispheres and the four brain lobes. Knowledge of this will assist in understanding how brain herniation occurs in response to increased intracranial pressure. The dural folds are (Jones 2021):

- Falx cerebri – separates the right and left cerebral hemispheres.
- Falx cerebelli – separates the left and right cerebellar hemispheres.

Box 1. Typical symptoms of a cerebrospinal fluid (CSF) leak

- Balance and gait issues
- Blurred or double vision
- Dizziness or vertigo
- Hearing changes or loss
- Hearing a pulse in the ears
- Headaches
- Leakage from the nose or ears
- Light sensitivity
- Loss of appetite
- Loss of sense of smell
- Nausea and vomiting
- Neck pain and stiffness
- Seizures
- Tinnitus

(Brain Charity 2022)

» Tentorium cerebelli – separates the occipital and temporal lobes from the cerebellum and provides a passage for the midbrain (the top part of the brainstem), called the tentorial notch.
» Diaphragma sellae – lines the sphenoid bone as part of the pituitary fossa. This provides an opening for the pituitary stalk, which connects the pituitary gland to the brain.

Brain herniation is a medical phenomenon that occurs when increasing intracranial pressure causes brain tissue from one intracranial compartment to move into another intracranial compartment (Knight and De Jesus 2020). It is a sign that compensatory mechanisms stated within the Monro-Kellie doctrine cannot keep the intracranial pressure stable, as the intracranial volume has become critical.

The most common types of brain herniation are (Munakomi and Das 2023):

» Uncal herniation – caused by a mass lesion such as an extradural haematoma causing the innermost part of the temporal lobe (the uncus) to be pushed towards the tentorium cerebelli. This exerts pressure on the midbrain, which compresses the third cranial nerve, causing pupil dilation.
» Central (transtentorial) herniation – central structures such as the diencephalon (thalamus, hypothalamus and limbic system) and parts of the temporal lobe are pushed through the tentorium, putting pressure on the cerebellum. It can also cause pontine haemorrhage, which can be identified by pinpoint and unreactive pupils.
» Subfalcine herniation – a curved fold called the cingulate cortex is pushed under the falx cerebri. The cingulate cortex covers the corpus callosum of the limbic system (a set of structures in the brain that have a vital role in emotion formation and processing, learning and memory formation).
» Tonsillar herniation – the cerebellar tonsils are pushed down into the foramen magnum, an opening in the occipital bone of the skull where the medulla oblongata connects to the spinal cord. This causes ischaemia of the brainstem, which leads to respiratory and cardiovascular dysfunction. This is often referred to as 'coning'.
» External (transcalvarial) herniation – brain tissue is forced through a fracture line in the skull. This can be performed as a preventive measure to relieve intracranial pressure in a procedure called a craniectomy.

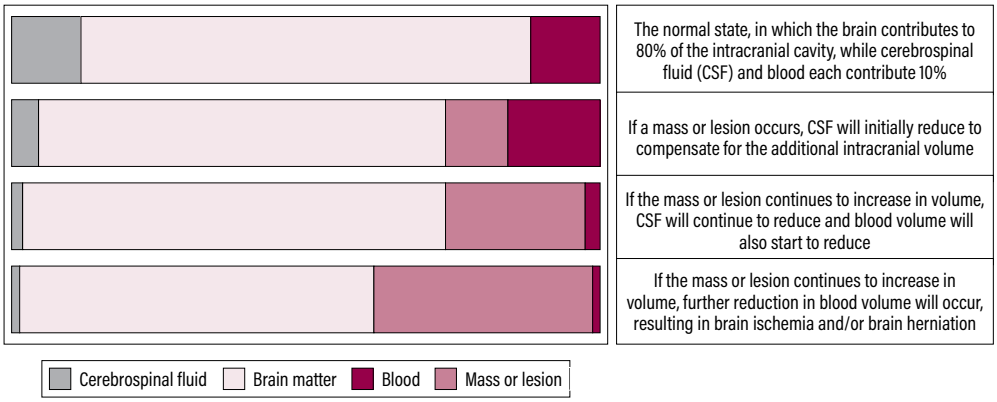
Critical signs of brain herniation include (Debevec-McKenney and Gillespie 2023):

» Decorticate or decerebrate posturing – transmission through the rubrospinal and corticospinal tract is interrupted due to increased pressure within the skull, particularly the midbrain, as a result of central herniation. Decorticate posturing is indicative of central herniation, while decerebrate herniation can indicate the start of tonsillar herniation (Munakomi and Das 2022).
» Bilateral dilated pupils (anoxia mydriasis) – caused by transtentorial herniation or anoxia, leading to global ischaemia (Adoni and McNett 2007).
» Reduction or loss of brainstem reflexes – this includes blinking and the gag reflex.
» Loss of consciousness or becoming comatose.
» Respiratory and/or cardiac arrest – resulting from ischaemia to the brainstem, causing reduced respiratory and cardiovascular autonomic regulation.

Conclusion

It is essential that children's nurses understand the pathophysiology of ABIs to

Figure 3. Relationship between intracranial volumes where there is an intracranial mass or lesion



support the early recognition of neurological deterioration in children and young people. Children's nurses also need to be able to identify signs and symptoms of neurological deterioration to prevent secondary injuries to the brain, thus increasing patients' chances of recovery. Understanding the underlying pathophysiology is also relevant to the second article, which will explore how to perform a neurological assessment.

TIME OUT 4

Identify how undertaking neurological observations in infants, children and young people applies to your practice and the requirements of your regulatory body

TIME OUT 5

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: **rcni.com/reflective-account**

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Neurological observations: part 1

TEST YOUR KNOWLEDGE BY COMPLETING THIS MULTIPLE-CHOICE QUIZ

1. Acquired brain injuries (ABIs):

a) Always have traumatic causes ☐
b) Include injuries to the brain that occur during fetal development ☐
c) Can have traumatic or non-traumatic causes ☐
d) Do not include any alteration to brain function or pathology due to an external force ☐

2. Which statement is false?

a) A child's head is heavy, large and rests on a neck that is not well supported, so head and cervical spine injuries may easily occur ☐
b) Children have a lower chance of acceleration-deceleration injuries and are less vulnerable to shearing forces within the brain than adults ☐
c) Children have a greater head-to-body weight ratio and weaker neck musculature than adults ☐
d) Young children are much more likely to fall head-first than older children and adults and therefore experience ABIs via this mechanism ☐

3. Acting on impulse and not thinking about the risks associated with one's actions is believed to peak in:

a) Infancy ☐
b) Childhood ☐
c) Adolescence ☐
d) Adulthood ☐

4. Diffuse ABIs may be caused by:

a) Hypoxia ☐
b) Infection ☐
c) Toxins ☐
d) All of the above ☐

5. Which of the following is a clinical presentation in children with an ABI to the frontal lobe?

a) Reduced or absent sensation ☐
b) Mood changes ☐
c) Hearing loss ☐
d) Slurred speech ☐

6. In infants, what is the most common cause of hospitalisation and death related to traumatic brain injury?

a) Falls ☐
b) Pedestrian injury ☐
c) Abusive head trauma ☐
d) Risk-taking ☐

7. Cushing's triad comprises:

a) Widened pulse pressure, bradycardia and irregular respirations ☐
b) Anaemia, dyspepsia and hypotension ☐
c) Pyrexia, tachycardia and dysphagia ☐
d) Nausea, hyperhidrosis and arrhythmia ☐

8. Typical symptoms of a cerebrospinal fluid leak include:

a) Leakage from the nose or ears ☐
b) Balance or gait issues ☐
c) Light sensitivity ☐
d) All of the above ☐

9. What is external (transcalvarial) herniation?

a) When brain tissue is forced through a fracture line in the skull ☐
b) When a curved fold called the cingulate cortex gets pushed under the falx cerebri ☐
c) When central structures such as the diencephalon and parts of the temporal lobe are pushed through the tentorium, putting pressure on the cerebellum ☐
d) When the cerebellar tonsils are pushed down into the foramen magnum ☐

10. Which of these is not a critical sign of brain herniation?

a) Reduction or loss of brainstem reflexes ☐
b) Constricted pupils ☐
c) Loss of consciousness ☐
d) Decorticate or decerebrate posturing ☐

How to complete this assessment

This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question.

You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently.

You may want to write a reflective account. Visit rcni.com/reflective-account

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This multiple-choice quiz was compiled by **Alex Bainbridge**

The answers to this quiz are:

1. c, 2. b, 3. c, 4. d, 5. b, 6. c, 7. a, 8. d, 9. a, 10. b

This activity has taken me ___ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

Excellent ☐ Good ☐ Satisfactory ☐ Unsatisfactory ☐ Poor ☐

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