ORIGINAL ARTICLE

The experiences of family carers in the delivery of invasive clinical interventions for young people with complex intellectual disabilities: policy disconnect or policy opportunity?

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Aims and objectives. To explore the experiences of family carers in the delivery of invasive clinical interventions within community settings.

Background. Many young people with intellectual disabilities present with complex health needs and require clinical interventions to sustain life. As the population lives into older age there is growing demand for the delivery of these interventions within the community setting.

Design. An interpretivist qualitative design.

Methods. Ten family carers of children with intellectual disabilities and complex care needs requiring invasive clinical interventions participated in semi-structured interviews.

Results. There are barriers identified regarding the delivery of invasive clinical interventions in the home setting by social care support workers. These include a reluctance to carry out invasive clinical interventions both for family carers and staff, anxiety, a lack of knowledge and training and difficulties in recruiting appropriate staff.

Conclusions. There needs to be strategic policy developments focusing on this population who are cared for in the community and require invasive clinical interventions.

Relevance to clinical practice. Registered Nurses have a key role in educating and preparing families and social care support workers to safely deliver invasive clinical interventions in community settings for both children and adults with intellectual disabilities.

Key words: community care, co-production, education and practice development, health needs, intellectual disabilities, invasive clinical procedures, nurses, nursing, policy implementation, support workers

What this paper adds to the global clinical community

- As the number of children with intellectual disabilities and complex physical needs increases and live into adulthood, more will require access to invasive clinical interventions to maintain their health and enable social inclusion following the move away from institutional to community-based models of care.
- Parents and registered nurses are the main providers of invasive clinical interventions in childhood and they have a role to play in educating and prepare social care support workers as young people transition from the care of child health onto adult community care services.
- Strategic service developments need to take place, supported by local operational policies to enable wider access to invasive clinical interventions, with registered nurses using their knowledge and skills to educate and prepare social care support workers to meet future care needs of this population.

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Introduction and Background

Due to increasing life expectancy there is a rise in the number of children and young people with intellectual disabilities living into adulthood with complex physical health needs, with some dependent on technological interventions to maintain their health and sustain life (Glendinning *et al.* 2001). The majority now live in the community and as life expectancy improves there is a growing demand for health and social care interventions, including invasive clinical interventions (ICIs), with implications for services and care delivery in the future (Bardsley *et al.* 2011, World Health Organisation 2011). There is significant literature about the role of parents when meeting the needs of their child with long-term health conditions (Fisher 2001, Heaton 2005, Coffey 2006, Hallstrom & Elander 2007, Tong *et al.* 2008, Smith *et al.* 2013, Whiting 2014). Yet there has been limited attention on the training and skills required by the staff who work with parents in caring for their child within the community and how and by whom the ongoing long-term health conditions and ICI delivery will be addressed in adulthood. It is therefore necessary to identify the services and skills required to meet the needs of this population with long-term health conditions and the delivery of ICIs in the future.

Invasive clinical interventions

ICIs are interventions that are traditionally carried out by healthcare professionals to assess, maintain, treat or improve health and sustain life. ICIs can include both invasive and noninvasive procedures (Bulechek *et al.* 2008) and can be therapeutic or diagnostic (METeOR 2005). Henderson and Knapp (2005) refer to the measures taken to resuscitate a patient as an 'invasive intervention', and '*The Keys to Life*' (Scottish Government 2013:102–3) state that invasive interventions are 'not only life enhancing but lifesaving'. At present there appears to be no internationally agreed definition for a health care intervention that is invasive, and the terms 'procedure' and 'intervention' are often used interchangeably (Gerrard *et al.* 2010). Having reviewed the literature and noting the lack of an accepted definition, the researchers developed the following definition: 'An ICI involves close personal contact between the provider and patient when a foreign object invades the body, including the puncturing of the skin, to enable the insertion of clinical devices to allow for the administration of nonoral medication and ongoing care following procedures, such as catheter and stoma care'. For this paper the term ICI will be used.

In 2008 the Royal College of Nursing (RCN) set out the range of ICIs that could be delivered to children following preparation under supervision by registered nurses for non-registered practitioners, such as Health Care Support Workers. The RCN suggests that preparation should occur at two levels: (1) general education about complex needs and (2) specific education and preparation about the needs of the individual and the ICI to be delivered (Royal College of Nursing 2012: 5). There are further specific key elements which need to be incorporated into a program, set out in Table 1.

Within child health services ICIs are usually delivered by family carers, such as parents, registered nurse and by trained and supervised Health Care Support Workers, employed by healthcare services under the supervision of registered nurses. There is no defined equivalent set of ICIs for adults that may be delegated by registered nurses to nonregistered health practitioners and while the RCN publication relates to children, there is relevance to the carers of adults who require ICIs.

A systematic review of the literature undertaken by Hithersay *et al.* (2014) highlighted that carers of adults with intellectual disabilities in the community undertake interventions in three main areas (1) the delivery of screening procedures, (2) interventions to promote and improve health and (3) interventions to improve cognitive functioning, coping skills and the management of pain. The authors found no previous research relating to the delivery of ICIs by nonregistered practitioners such as social care support workers. This raises the question of what happens when children reach adulthood and make the transition from child health services into adult care and where practitioners take on the role of safely and effectively delivering ICIs. It is therefore, important to more fully understand what is occurring within the childhood population with regards to the role of registered nurses in supporting and training

Table 1 Specific elements required to enable invasive clinical interventions (ICI) delivery

A competency-based approach to delivering ICIs
Agreed individual clinical protocols for ICI delivery
Written individual goals for ICI delivery
Audit cycles – regular updating and reassessing of competence
Evaluation criteria of ICIs
Statements of service provision and professional accountability
Confidentiality for service user and families
Care of the ICI equipment
Medical device education
Emergency management and risk assessment

Adapted from Royal College of Nursing (2012: 5).

nonregistered practitioners so as to enable the safe delivery of ICIs when the young people make the transition into adult services.

The study

Aims

There were two broad aims of the study (1) to explore the experiences of family carers in relation to nonregistered practitioners delivering ICIs for their child with intellectual disabilities and (2) to explore the future role of registered nurses and Social Care Support Workers in delivery of ICIs.
   The study questions were:

1 What are the experiences of family carers in relation to the delivery of ICI for their family member?

2 What preparation and support do family carers receive in relation to ICI delivery for their family member?

3 What do family carers view as the role of registered nurses in the preparation and training of nonregistered practitioners in relation to delivering ICIs?

4 How do family carers view the future of their family member requiring ICIs?

5 What barriers stand in the way of the safe delivery of ICIs by nonregistered practitioners and how might they be overcome?

Design

The primary focus of the study was on the experiences of family carers to identify and develop the understanding of the current and future delivery of ICIs and the role of registered nurses and nonregistered practitioners, therefore an interpretivist approach was adopted (cf. Atkinson *et al.* 1988, Denzin & Lincoln 2000, Crotty 2005). Semi-structured interviews were identified as the most appropriate methodology to explore the views of carer's of the delivery of ICIs within the home setting for their family member with intellectual disabilities.

Participants

Participants were selected because of their knowledge and experience as family carers of children and young people with complex care needs in receipt of ICIs, thereby forming a purposeful sample. The sample participants were recruited from geographical areas across Scotland which included: Fife, Glasgow, Renfrewshire, Lanarkshire and Stirlingshire. Demographic data were collected from the families who consented to take part in the study. The age

of the children currently receiving ICIs ranged from 2–16 years of age. Five of the families had a least one other child in the family. The children of the families recruited had a variety of diagnoses including genetic conditions such as Down's syndrome and Edwards syndrome, cerebral palsy – including quadriplegic and athetoid cerebral palsy, microcephaly and profound and multiple learning disability (PMLD). Across the age groups of the children a range of ICIs were undertaken, with the most common intervention reported being nutrition provided via a gastrostomy. Others ICIs delivered included: oxygen delivery, suctioning – both nasal and oral, nebuliser delivery, tracheostomy care and nasogastric tube feeding. High levels of personal care and manual handling were reported for all children.

Recruitment

Participants were accessed through local and national voluntary organisations and charities, with contact initially made with 19 families who were interested in the study and met the inclusion criteria. Ten ($n = 10$) families were finally recruited; the others did not participate due to a variety of reasons such as not responding to requests after initial contact or their child becoming suddenly unwell. The majority of interviews were undertaken with the mother of the child ($n = 9$) and for one interview, both parents were present.

Data collection

A semi-structured interview schedule was developed by the research team, as set out in Table 2. Interviews took approximately one hour. A total of $n = 10$, face-to-face semi structured interviews ($n = 9$) and telephone interviews ($n = 1$) were conducted with parents of children with intellectual disabilities receiving ICIs between October 2013– February 2014.

Ethical considerations

The *University Research Ethics and Governance* Committee independently reviewed the study and granted approval. All research ethics and governance procedures were adhered to throughout.

Data analysis

The interpretative approach was deemed appropriate as it aims to be exploratory, thereby developing insights and understanding of the phenomenon under investigation and

Table 2 Focus of the semi-structured interview schedule

The definition of invasive clinical interventions (ICIs)
The range of ICIs required by the child
The practitioners involved in the care of the child
The education and preparation provided to deliver ICIs
The provider of the preparation
The assessment of knowledge and skills to enable the delivery of the ICI
The knowledge and skills required by staff to deliver ICIs, family involvement in assessing competence and barriers and solutions to enable ICI delivery
The ongoing education and support required to enable ICI delivery
The role of direct payments in enabling care and the provision of ICIs in the future and the relinquishment of care

Table 3 Key themes arising from the analysis of the data

Invasive clinical interventions (ICI) definition
Individuals involved in the care of children in need of ICIs
Barriers to ICI delivery
Education of family carers
Education of practitioners
Family carer role in the education of practitioners
The future

Table 4 Groups involved in provision of care

Groups involved in care
Classroom staff and home teachers
Community nurses and community children's nurse
Dieticians
Family Friends
Holiday program staff
Occupational therapists
Paediatrician
Parents and other family members
Physiotherapists
School nurses
Social workers
Specialist nurses, such as gastrostomy nurse, respiratory nurse
Support staff

does not seek to generalise or offer quantitative reliability (Parahoo 1997). Thematic analysis was employed and was viewed as the most appropriate by enabling analysis, identification and reporting of thematic patterns from within the data (Strauss & Corbin 1990, Braun & Clarke 2006). The interviews were transcribed verbatim and analysed individually and collectively for consistency, with the researchers systematically analysing and reanalysing the data to identify recurring themes and develop a set of thematic categories (cf. Ritchie *et al.* 2008). An integral part of the data analysis process involved taking field notes during the interviews which assisted the research team to identify important and relevant themes and formed the basis of further discussions and agreement. QSR NVIVO (Version 10, QSR International Pty Ltd, Victoria, Australia) was used to manage the data and to ensure a reliable and systematic analytical approach was utilised throughout (Bazeley 2008).

Results

Seven key themes were identified from the analysis of the data, as set out in Table 3.

Invasive clinical interventions definition

All interviewees were asked to comment on the definition developed by the research team regarding an ICI. All were asked if this definition resonated, with some stating that it was 'a pretty fair summary' (Parent Interview 1) and accurate. One went on to suggest that some ICIs could be viewed as more invasive than others, such as caring for a tracheostomy compared to nutrition via a gastrostomy. Therefore in the absence of a universally recognised definition, the researchers offer the one set out earlier in this article.

Individuals involved in the care of the children in need of ICIs

During the interviews when talking about the delivery of the ICI, a range of people and professional groups were involved in the child's care, set out in Table 3. With regards to family and friends, some participants indicated that it might not be appropriate for some family members, such as grandparents and siblings, to be involved in delivering ICIs or that family members or friends were not comfortable undertaking the role.

Barriers to ICI delivery

The participants highlighted that one of the barriers was their reluctance to carry out some procedures. For some, there was increased anxiety and reluctance to undertake tasks such as changing a gastrostomy tube:

…the one thing we have not been trained in, we've resisted is if the button comes out obviously to be able to replace it and I can do many things for my son but the thought of doing that and getting it wrong just terrified me, so that's the one thing we would take him to hospital to get done. (Parent Interview 3)

This view was also similar when participants were thinking about other individuals delivering ICIs: 'we often

find nurses are not very keen on suctioning' (Parent interview 3) and this could create difficulties for the child's care and for parents. It was considered that a lack of knowledge or understanding could lead to anxiety and fear for the individual expected to carry out the ICI and could cause concern for parents, particularly if the practitioner delivering the ICI was nonregistered: 'there has been instances that we wouldn't leave him with certain people 'cause they're not quite confident enough or trained as well' (Parent Interview 4).

A barrier identified related to staff attitudes with participants highlighting that if they perceived that the attitude was not appropriate or if they had concerns, they would not let the individual undertake an ICI or be left alone with their child:

…it couldn't just be anybody; it'd have to be somebody I could trust, somebody who has medical background that knows enough about what to do. I'm quite fussy with that cause, I mean, I couldn't just leave (child) with anybody, I'd have to make sure they knew enough. (parent interview 10)

Some stated that they could not recruit appropriate staff to undertake the work with their child and suggested that this might be due to not being able to finding someone willing to undertake the role or due to organisations being short staffed and unable to provide appropriately trained staff.

Education of family carers

It is important to understand the training that parents had received in terms of ICI delivery, as many who participated in the study reported having to train the staff providing care for their child. Participants described their own preparation to deliver an ICI, and how they were shown the procedure by a health professional: 'so a nurse in the hospital taught me' (parent interview 10), who also described the procedure and then they were supervised carrying out the ICI in the hospital. In one case a participant described the use of training dummies before undertaking the procedure on their child. Parents reported that their child was not discharged home from hospital until their knowledge and skills has been assessed and that the nurses were satisfied they could manage to safely deliver the ICIs at home:

…It'd be fair to day we generally get released from (the hospital), so they're, you know, not really prepared to release us unless they're happy and ultimately we're happy that we've been trained. (parent interview 4)

Despite the preparation, some parents were of the view that they were not adequately prepared to carry out ICIs at home: 'I didn't feel well trained when I left hospital as all. I was all fingers and thumbs and pretty nervous' (parent interview 8).

The participants were asked about ongoing education, with the majority reporting that their knowledge and skills had never been reassessed and they had not been offered any form of education or practice update. Some suggested that if they needed further support or training, they would ask, while others stated they would like updates, yet felt that it should be the responsibility of the health and social care support workers to provide them: 'I kind of think that maybe that (ongoing training) should be offered to parents actually, is that they should approach you' (Parent interview 4).

Education of practitioners

Participants were asked about the training of staff who provide ICIs for their child. In terms of staff the focus was on nonregistered health practitioners, such as social care support workers. With regards to the delivery of ICIs in the school environment, none of the parents had given the training of staff much thought, and assumed that the staff would be trained appropriately by the school or care organisation: 'I would expect them to have had the training…so as far as I'm concerned they've had the training that they need' (Parent interview 2). This was different to the views expressed by parent regarding home support staff where they had direct involvement in the education of support staff and highlighted that staff need to understand the importance of delivering an ICI correctly:

…and likewise with the feeding, especially with NHS feeding, they need to understand that if they don't pass that tube correctly and they don't test that it's in the right place then that is bad, bad news. So I think to understand the consequences, it is important the people to appreciate. (parent interview 3)

It was reported that having theory, practice and supervision were all important components of training and that it did not have to be a registered nurse delivering the ICI providing the individual were adequately trained and supervised. Some participants were of the view that in addition to the general training, the member of staff should also be trained for their child, for example:

…I think the important thing is that they have child specific knowledge as well as a general theoretical background of how to carry out the skill they actually need to be, I suppose, trained to

work with that child because every child's going to have, well obviously, a unique kind of tolerance for different procedures. (Parent interview 9)

Other participants commented that it would be useful for staff to have formal recognition by way of signoff documentation to evidence that they have been trained and were competent in delivering specific ICIs:

…I think it is always good to have something on paper in case there's any come back, you know, something just to say that they've been signed off. I know that even, I've just changed (child) button for the first time. Supervised by one of the community nurses, and that all had to be signed off, so I'd rather it was documented. (Parent Interview 7)

Family carer role in educating practitioners

Participants described how they had been involved in the preparation of staff who would care for and diver ICIs for their child. They were of the view that they should play an integral role in the education and preparation of staff who would come into their home and that it was central to providing the best possible care:

…I mean a nurse for instance would train somebody to suction, they might not have dealt with (child), whereas we deal with (child) all the time so we can give them all the wee hints and times about if you do this and if you don't do that and this is the best way to get the best suction, cause we know him better than anyone else, so I think it would be almost a bit silly to train staff without our input as well. (Parent interview 1)

Some participants highlighted the need for them to supervise staff to ensure that they could independently deliver the ICIs, with some reporting that they had taken on the training of their home care staff:

…I just witnessed the care staff doing what was required and after telling them how it was done and what to do and things, I then witnessed then doing it and then I was quite happy enough to carry on. (parent interview 9)

…it's very straightforward but I had to go through it [training] with every care worker than came along I had to do it with everybody. (parent interview 4)

The future

When asked about the future several of the participants indicated that they had not really thought about the future and for those that had, there was concerns about the lack of suitable services and staff. Some parents highlighted their intention to keep their adult child at home, others about the need for residential support their child when older:

…Well I would love it if he was able to be supported in a home kind of setting with live in care. I would think that would be the best possible scenario for him. (parent interview 9)

There was much anxiety raised about the provision and availability of services as a child moved into adult services:

…We are worried about the future and what it'll mean and from what I can hear from other people, it is once a child moves into adult services you can get nothing and for our point of view that would mean that we both would have to pack in work and that has obviously significant consequences. (parent interview 3)

Parents highlighted that they would require ongoing services when their child moved into adults services; particularly for families who wished for their child to remain living within the family home: 'I would like there to be some sort of provision, perhaps a day service he can go to and that he can enjoy' (parent interview 3), 'well he'll go to some sort of day centre I suppose, replacement of school' (parent interview 4).

Discussion

The population of children with intellectual disabilities living into adulthood is increasing, with many presenting with lifelong physical conditions, a phenomenon that will continue (Oeseburg *et al.* 2011). As a consequence more people with intellectual disabilities will require ICIs that are now being delivered in the family home and social care rather than health settings (Elias & Murphy 2012). To enable the delivery of person centred care, there will be an increasing demand for families and social care workers to deliver ICIs and for health practitioners, such as registered nurses, to prepare them for the role. There are therefore important issues arising from this study that need to be considered in terms of future service delivery models and wider workforce needs, notably the role of registered nurses in preparing and supporting family carers and social care support workers to undertake ICIs (Department of Health 2013).

From the perspective of parents, many want to continue their caring role for their adult child after their other adult children have left home (Seltzer *et al.* 2011). Family carers, often ageing parents, are therefore key to care delivery of their adult children with intellectual disabilities within the family home context. To ensure that their ongoing caring role remains a reality there are potential barriers that need to be considered and solutions found. A potential barrier

relates to the reluctance of parents to undertake ICIs; this may be the case for some social care support workers too. Other issues that need to be considered and that are of importance to families are the attitudes of support staff providing care within the home setting. The recruitment and retention of staff with the right attitudes and values needs to be addressed and there are practice development and workforce issues that need to be considered and planned for now to ensure there is the right workforce available (Bigby *et al.* 2014). Without willing and appropriately prepared support workers, it will not be possible to deliver ICIs safely and effectively in the home or social care setting. Ensuring that the social care workforce have the education, preparation and supervision once trained to deliver ICIs must be planned for in partnership with registered nurses who will in turn need to develop their role to ensure these workers are competent and remain so (Wark *et al.* 2014).

The health needs of children and adults with intellectual disabilities are dynamic and change overtime and as a consequence reassessment and review is required to ensure that packages of care are fit for purpose and that parents and staff providing ICIs have the up-to-date knowledge and skills required (Boyle *et al.* 2011). With regards to education, parents reported that when their child was first in hospital they received good training and guidance, highlighting that both theory and practice were important in training them about the ICIs they would deliver. However, there appears to be a lack of ongoing education, skills refreshers and training updates, vital to ensure their knowledge and skills remain up-to-date (Wark *et al.* 2014). Assumptions were made by parents that school staff already had the skills and had received training therefore they had little involvement in preparation. This however was not the case for home-based support staff and parents had a key role in their education and supervision. While this is understandable, it is a cause for concern if parents are not receiving regular updates and refreshes to ensure their own practice is safe and up-to-date before they skill share with support workers coming into their home. Robust education, preparation and support for parents is therefore a key issue as some feel anxious about their own abilities to undertake ICI and given the increasing demand in the future, this is a strategic issue that needs to be recognised and planned for. At present it appears that ICI education for parents and social care workers is patchy and opportunistic with no clear programme or means of assessing and evidencing competence or providing ongoing support and supervision. The absence of a planned and coordinated strategic approach to education, preparation and supervision

therefore offers the opportunity to offer accreditation for parents to delivery ICIs (Agranoff 2013).

While parents recognise that there will come a point when they will need to relinquish the care of their adult child, it was apparent that some had not given it much thought. However, for those that had or were already starting the transition process, there were concerns about the availability of suitable service provision and how needs will be met within adult car services (Betz 2004, Kennedy & Sawyers 2008). Central to this process is the need for early, effective transition planning by care funders and providers that includes an up-to-date assessment of need and care plan that includes ICI delivery and clearly sets out the education of parents and support workers (American Academy of Pediatrics 2011). Registered nurses have an important and central role in the assessment, design, delivery, evaluation of education programmes and the decision whether to delegate ICIs, paramount for safe care (Royal College of Nursing 2012). As registrants, registered nurses retain accountability for their actions, including safe delegation to others. It is therefore important that health services ensure that all registered nurses involved in the process fully understand the implications of skill sharing and delegation and their ongoing role and responsibilities when delegating (Standing & Anthony 2008, Royal College of Nursing 2012, Hasson *et al.* 2013).

Part of the package of care for people with intellectual disabilities requiring ICIs is respite breaks. This adds another dimension to the delivery of ICIs as respite care workers will also need to be included in the education, preparation and supervision. At some point in the life of their adult child, parents may opt to or need to relinquish care, and planning for these to ensure that care providers are identified, support workers recruited and prepared to safely deliver ICIs (Nankervis *et al.* 2011). As more people with intellectual disabilities require ICIs, there will be increasing demand for packages of care within and out with the family home setting. As a result there are wider strategic workforce and resource issues that must be identified and planned for by health services, social care and care providers to meet future demand (Agranoff 2013).

Given the increasing needs of this population, there is a need to strategically develop models of care and education that safely meets the needs of young people with intellectual disabilities who require ICIs as they progress into adulthood. Part of the solutions rest in the need for strategic workforce planning and ICI skills sharing and development across health, social care and care providers to ensure that there is a knowledgeable and skilled workforce for the future (Buchan & Seccombe 2011). Parents are key partners

in their adult child's care and their development needs must be identified and met too, not only those of professionals. It is therefore important to ensure that education and preparation reflects future workforce needs and that health services, social care and care providers develop capacity to enable the delivery of ICIs (Department of Health 2013).

Conclusion

There has been a major policy and service changes in the care of people with intellectual disabilities from institution to community home-based care. These changes are positive however there now appears to be an emerging policy disconnect due to the absence of a focus of the needs of this population who require ICIs in the future. There is therefore a window of opportunity that needs to be grasped to ensure there is a reorientation of care services to ensure they have the capacity and infrastructure to meet future needs. Strategic vision, investment and development are required to enable the delivery of safe, person centred home-based care with families and patients at the heart. No literature was identified regarding the education, preparation and supervision of social care support workers on the delivery of ICIs for adults with intellectual disabilities.

Registered nurses have an important role in the preparation of parents and the social care workforce in the provision of ICIs and service providers need to ensure governance, education and supervision systems are developed to ensure that care is safe and effective. There is therefore an opportunity and need for further research into the opportunities and challenges faced by family carers and professionals as the current evidence-base is underdeveloped.

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