What are the optimum research approaches to investigate the health care experiences of children with long-term conditions within the infant school setting? A research proposal

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Abstract

Children and Young People (CYP) are an under researched group in the literature for a number of reasons. The reasons for this include concerns about ethics, appropriate research methods and children's developing cognition. This proposal reviews the policy drivers and current literature promoting CYP's perspectives as service users of health care. It considers rationales for research methodologies and approaches that can engage CYP throughout the research. There is an increasing population of CYP with Long Term Conditions (LTC) attending main stream school. It is important that their experiences within the setting are explored in order for them to achieve their potential from health, social and educational perspectives. This research proposal aims to explore the experiences of managing a LTC from children's, parental/carers and school staff perspectives in the infant school setting. It is anticipated that this preliminary research proposal could contribute to the evidence base to inform targeted, responsive support for children in this setting.

Introduction

This research proposal will explore approaches to undertaking research with CYP, which promotes and values their involvement as users of health services. The experiences of CYP are unique and separate from their parents/carers and it is important that these perspectives are actively sought, valued and responded to, particularly in school settings where children exist as individuals independent from their parents/carers. Children transitioning to infant school will have specific needs relating to developing responsibilities for managing aspects of their LTC and it is vital that research is undertaken to understand the child's perspectives.

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The engagement of CYP as Service Users of Health Care

Service user (a term which has been selected for this proposal to include patients, public, carers, care givers, clients, consumers and family) involvement has been a feature of health care policies directing the NHS modernization agenda for more than a decade (Department of Health {DOH} 2000, 2003, 2004, 2006, 2008 & 2010). Service user involvement has the potential to raise standards of health care, the responsiveness of services and health outcomes, whilst empowering service users and redressing some of the power imbalances with providers (Repper & Breeze 2007). However, evidence suggests that whilst service user involvement in health care has increased, there are disparities between the philosophies and practicalities of their involvement (Lathlean et al 2006). The potential for the involvement of CYP as service users may be inhibited by ethical concerns and lack of understanding of the skills required when consulting with children (Alderson & Morrow 2011).

CYP require specific health care services which are developmentally responsive to their needs as they differ from adults in terms of their developing cognition, autonomy and independence (Coad & Shaw 2008). The requirements to ensure CYP's views individually and collectively are valued and responded to come from international, national and legal conventions for example; the United Nations Convention on the Rights of the Child (UNCRC 1989), the National Service Framework for CYP and Maternity Services (DOH 2004a) and the Office of the Children's Commissioner (Children's Commissioner for England 2014). To champion the meaningful contributions of CYP in health services, the Royal College of Paediatrics and Child Health (RCPCH) recently produced a toolkit facilitating safe and ethical involvement (RCPCH 2010). However, Coad & Shaw's (2008) scoping review of the evidence for CYP's involvement in health care demonstrated good practice examples but limited evidence as to whether this involvement led to a more responsive health service for CYP. It is anticipated that consultation with a CYP and a parents 'service user' steering group would be central to and inform the design, implementation and analysis of the findings of this research proposal.

Considerations when researching with CYP

This section of the proposal overviews some of the considerations when researching with (as opposed to 'on') CYP and the approaches used. It could be assumed that adults know what CYP would require from health care services. Adults have been through childhood so could, by default, have insight into what CYP require. This assumption has been challenged in the literature, since adults are unable to re-enter childhood and their constructs of it are based upon their assumptions about childhood and indeed their own life experiences (Punch 2002).

Children are ascribed a lower position in an adult led society which may affect their ability to fully engage with an adult researcher. This can impact upon the validity and reliability of the research (Punch 2002). Mauther (1997) argues that in order to address the unequal power relationships between adults and children, child centred approaches to data collection that view children as subjects rather than objects of research can help to redress some of the imbalances. Coad & Evans (2008) contend that in order to gain a greater understanding of CYP perspectives and priorities, their involvement should extend to data analysis processes. This approach is similarly advocated in Public Patient Involvement (PPI) research, whilst also encompassing broader public involvement such as involving the public in research applications, identification of research priorities, as members of steering groups, undertaking interviews with research participants or carrying out the research (National Institute for Health Research {NHIR} 2012).

Assumptions about children's developing cognition, vocabulary, language and communication skills can be perceived by adult researchers as limiting their ability to participate in valid and reliable research (Punch 2002). However, the child's language may not necessarily reflect their cognitive abilities (Horstman et al 2008). Woodhead (1998 cited in Punch 2002) cautions that models of child development are not universally applicable, being culturally and socially specific. Driessnack (2006) argues younger children will typically understand more than their verbal reports suggest. Indeed Driessnack (1996) argues that

although young children may use limited language, they may use different language that adults do not understand, impacting upon adult researchers' interpretations.

Kirby (2004) collaborated with a range of researchers and young people to compile guidance (aimed at researchers and managers) for actively involving CYP in research. This proposed flexible and creative approaches to meaningful (as opposed to tokenistic) involvement, considering how the processes can highlight CYP competencies and prioritise CYP involvement in all stages of research, whilst overcoming professionals anxieties about CYP involvement (Kirby 2004). This proposal aims to prioritise CYP involvement throughout the research process, encompassing the PPI research goals (NIHR 2012).

However, it is acknowledged that research involving collecting and reporting views of CYP raises ethical questions and must ensure their well-being is protected, adhering to research ethics committees' standards to respect CYP rights and protect them from harm (Alderson & Morrow 2011). The nature of research with children involves inherent methodological considerations including (but not limited to) gaining informed consent, accessing CYP, respecting privacy and confidentiality (Mauther 1997) and ethical issues can be the focus of concerns when researching with children (Punch 2002). The power imbalances between the child and the perceived authority figure of the adult researcher require careful ethical consideration (Horstman et al 2008). However, over protecting CYP would lead to harm and the exclusion of their voice from research, therefore new ways of addressing the ethics when researching with children need to be developed (Alderson & Morrow 2011).

In order to redress the inequalities when filtering CYP perceptions from the perspectives of the adult researcher, a range of participatory research methodologies for researching with CYP have been proposed (Coad et al 2009). These differ from traditional research methodologies in that participatory methods aim to engage children in an equal relationship, which is meaningful, active rather than passive, relevant and comfortable to them (Coad et al 2009). These participatory methods have been adapted

from work with adults, so have relevance for application with both children and adults (Punch 2002). It is suggested that participatory methodologies harness the competencies of children, providing enjoyable and interesting involvement which they can relate to, for example, through the use of drawing which is a familiar childhood activity that can enable them to control and share their perceptions (Carter & Ford 2013, Punch 2002).

A range of creative methods have been cited in literature for researching with CYP including paintings, drawings , graffiti boards (Coad et al 2009), combinations of drawing, writing & speaking 'Draw and write' (Backett-Milburn & McKie 1999, Horstman & Bradding 2002), photography, storytelling, crafts and play (Carter & Ford 2013) and keeping diaries (Mauthner 1997). Increasingly technology is being used when researching with children, such as in health service evaluations (Blakemore 2013). CYP like adults, are individuals that may have preferences for one method over another and by using a range of traditional and participatory methods this can be addressed, whilst ensuring the research remains interesting for the CYP (Carter & Ford 2013). The methodologies used will depend upon the competencies, experiences and preferences of the CYP, as well as the physical setting, research questions and competencies of the researcher (Punch 2002). The literature cautions that particularly careful consideration of data interpretation, analysis and robustness is required when using participatory research methods techniques (Backett-Milburn & McKie 1999, Coad et al 2009 & Carter & Ford 2103). The principles of PPI research could help to ensure the research focus and design reflects perspectives of CYP with a LTC (NIHR 2012). It is important to stress that a full and critical literature review of research methodologies will be undertaken as part of this research training and thus the selected methodology for this proposal under review.

The context of research relating to infant school children's experiences with LTC

In 2013, the Chief Medical Officer for England highlighted that compared

with similarly developed nations across Europe, the health outcomes for CYP with LTC in the UK are extremely concerning (Davies 2013 & 2014). Developing the evidence base to improve the health outcomes for CYP with LTC has been prioritised in the recent research call from the NIHR (Davies 2014). This preliminary research proposal is likely to be focused in the infant school context (key stage one), exploring childrens' experiences with managing their LTC to inform targeted support.

The lack of evidence relating to the effectiveness of self-care support interventions for CYP with LTC when compared with adults was highlighted by Kirk et al (2012a & 2012b). A review of the evidence base was undertaken, on behalf of The Health Foundation, with regards the impact of facilitating self-management interventions for individuals with LTC, which included CYP (de Silva 2012). This evidence supported self-management interventions, particularly those focusing upon behaviour change and supporting self-efficacy (de Silva 2012). Self-management interventions were shown to improve longer term health (including physical and psychosocial), self-efficacy (the individuals confidence in their ability to manage their health needs), knowledge of condition, problem solving skills, symptom management, motivations, behaviours and patterns of health serviced use (de Silva 2012). Supporting CYP to learn to manage aspects of their LTC is important to enable them to develop lifelong skills required to manage their condition/health.

Exploring how children manage their LTC in school settings could provide greater understanding of their school socialisation and health experiences, peer relationships and educational opportunities (which may contribute to their educational/employment opportunities in the longer term). However, there may be constraints within schools, families and in the child's desire to appear normal amongst their peers that may limit the adoption of self-management responsibilities (Meah et al 2009). The outcomes of this preliminary research proposal could contribute to the educational preparation of and service delivery from both school staff and professional health care teams (including specialist, school and public health services). This research is timely in light of the statutory guidance issued to schools in September this year from the Department for Education (DfE 2014). This sets out expectations to ensure pupils with medical conditions are fully supported in school settings (DfE 2014). This will require close partnership working relationships between health care professionals, school staff and families to enable children to achieve the best health and educational outcomes through full participation in school life (DfE 2014).

Meah et al (2009) noted the limited research exploring self-management in younger children with LTC, highlighting the parenting tensions in promoting the child's autonomy in this regard whilst ensuring their parental duty to protect their children. Parents /carers play a key role in encouraging children with LTC to learn to self manage elements of their condition and this is different to the role of the family in the context of an adult with a LTC. In parallel with the role of the parents, it is essential that research explores the experiences of the child in infant school settings, from their perspectives. This may be the first time the child, in their own right, as an individual pupil in the school setting, is expected to negotiate their needs relating to their LTC with a teacher instead of a parent (or a carer in a nursery setting). The perspectives of the school staff when assisting children in this regard could provide insights into the barriers to and facilitators of support required. This research proposal aims to explore these perspectives together to inform the evidence base for supporting children at this time of transition.

This preliminary research proposal aims to explore the experiences of children when managing their LTC in Key Stage One of infant school, alongside those of their parents/carers and school staff.

The following key lines of enquiry could potentially help to examine this:

• What are the experiences of children in Key Stage One when managing their LTC in the infant school setting?
• How do their families/carers negotiate the management of their child's needs in the infant school setting?
• What are the barriers and facilitators for school staff, when managing the needs of children with a LTC in the infant school setting?

The outcome of this proposal represents an opportunity to contribute to the evidence base, policy implementation, professional education and facilitation of supportive services for child with LTC in infant school settings.

References

Alderson P & Morrow V (2011) The ethics of research with children and young people (2nd Edition). London: Sage Publications

Backett-Milburn K & McKie L (1999) A critical appraisal of the draw and write technique. Health Education Research 14 (3): 387-398

Blakemore S (2013) App launched to record patient and family feedback. Nursing Children and Young People 25 (2): 5

Carter B & Ford K (2013) Researching children's health experiences: The place for participatory, child-centred, arts-based approaches. Research in Nursing and Health 36: 95-107

Childrens Commissioner (2014) Office of the Children's Commissioner Participation Strategy June 2014-May 2015. London: The Office for the Childrens commission.

Coad J & Evans R (2008) Reflections on practical approaches to involving children and young people in the data analysis process. Children & Society 22: 41-52.

Coad J E & Shaw K L (2008) Is Children's choice in health care rhetoric or reality? A scoping review. Journal of Advanced Nursing. 64 (4): 318-327.

Coad J, Plumridge G & Metcalfe A (2009) Involving children and young people in the development of art based tools. Nurse Researcher 16 (4): 56-64.

Davies S (2013) Annual report of the Chief Medical Officer 2012 Our children deserve better: prevention pays. Available from: https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays (Accessed 11 July 2014)

Davies S C (2014) National Health Institute for Research (NHIR) Long term conditions in children and young people themed call. Available from: http://www.themedcalls.nihr.ac.uk/children/about/cmo-message (Accessed on 25 June 2014)

Department for Education (DfE) (2014) Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England. London: Crown Copyright.

Department of Health (DOH) (2000) The NHS Plan: A plan for investment a plan for reform. London: Crown Copyright

Department of Health (DOH) (2003) Building on the best. Choice, Responsiveness and Equity in the NHS. London: Crown Copyright

Department of Health (DOH) (2004) Better Information, Better Choices, Better Health. London: Crown Copyright

Department of Health (DOH) (2004a) National Service Framework for Children Young People and maternity services. London: Crown Copyright

Department of Health (DOH) (2006) Our Health, Our Care Our Say. London: Crown Copyright

Department of Health (DOH) (2008) High Quality Care for All. NHS next stage review final report. London: Crown Copyright

Department of Health (DOH) (2010) Equity and Excellence: Liberating the NHS. London: Crown Copyright

de Silva D (2011) Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self management. London: The Health Foundation.

Driessnack M (1996) Draw and Tell conversations with children about fear. Qualitative Health Research 16 (10):1414-1435

Horstman M & Bradding A (2002) Helping children speak up in the health service. European Journal of Oncology Nursing 6 (2): 75-84

Horstman M, Aldiss S, Richardson A & Gibson F (2008) Methodological Issues when using the draw and write technique with children aged 6 to 12 years. Qualitative Health Research 18 (7): 1001-1011

Kirby P (2004) A guide to actively involving young people in research: For researchers, research commissioners and managers. Hampshire: INVOLVE

Kirk S, Beatty S, Callery P, Milnes K & Pryjmachuk S (2012 a) Perceptions of effective self care support for children and young people with long term conditions. Journal of Clinical Nursing 21: 1974-1987

Kirk S, Beatty S , Callery P, Gellatly J, Milnes L & Pryjmachuk S (2012 b) The effectiveness of self care support interventions for children and young people with long term conditions: a systematic review. Child: care, health and development 39 (3): 305-324

Lathlean J, Burgess A, Colham T, Gibson C, Herbert L , Levitt Jones T, Simons L & Tee S (2006) Experiences of service user and carer participation in health care education. Nurse Education Today 26: 732-737

Mauther M (1997) Methodological aspects of collecting data from children: lessons from three research projects. Children and Society 11: 16-28

Meah A, Callery P, Milnes L & Rogers S (2009) Thinking 'taller': sharing responsibility in the everyday lives of children with asthma. Journal of Clinical Nursing 19: 1952-1959

Nursing and Midwifery Council (NMC) (2010) Standards for pre registration nursing education. London: NMC

National Institute for Health Research (NIHR) INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research. Hampshire: INVOLVE

Punch S (2002) Research with children: The same or different from Research with adults. Childhood 9 (3): 321-341

Repper J & Breeze J (2007) User and care involvement in the training and education of health professionals: A review of the literature. International Journal of Nursing Studies 44: 511-519

Royal College of Paediatrics and Child Health (RCPCH) (2010) Not just a phase: A guide to the participation of children and young people in health services. London: RCPCH

United Nations Convention on the Rights of the Child (UNCRC) (1989) Convention on the Rights of the Child. London: HMSO