Self-care of young people with long-term physical and mental health conditions

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Supporting the Self-Care of Young People with Long-term Physical and Mental Health Conditions: Implications for Children's and Mental Health Nursing

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Abstract

Increasing numbers of children and young people experience long-term physical and mental ill health and how well they and their families manage their health and wellbeing is likely to influence their health in adulthood and their future life chances. This paper examines the evidence about 'what works' in supporting self-care in relation to children/young people with physical and mental health conditions. This is based on two systematic reviews and on research evaluating different self-support programmes that have been developed in the United Kingdom. We identify four key components of an effective and acceptable self-care programme that nurses can include when developing and providing such programmes for children and young people with long-term physical and mental health conditions. We also highlight the increasingly important role that children's and mental health nurses will play in supporting young people's self-care as a result of transformations in health care and nursing education.

Introduction

Increasing numbers of children and young people experience long-term physical and mental health problems. In relation to young people aged between 11 and 15 years old, 15% experience long-term illness or disability and 10% a mental health problem (Green et al 2005; Brooks et al 2011; Department of Health (DH)/NHS England 2015). Most of these young people are likely to face a life-time of managing their health and wellbeing. How well they (and their families) do this is likely to influence their health in adulthood and their future life chances.

For a number of years self-care and self-management have been emphasised in health policy in the United Kingdom (UK) (DH, 2005, 2006, 2012a,b; NHS 2014). This has been in response to the increasing prevalence of long-term illness and the associated financial costs to health services as well the influence of consumerism and a public desire for personalisation and control over health (Wanless 2002, DH, 2005). Although the importance of self-care and self-management are referred to in child health policies they have not been given significant emphasis (DH/Department for Education and Skills 2004; DH, 2009, 2015).

The conceptualisation and implementation of self-care and self-management in policy and practice has not been without criticism. It has been noted that although framed in a patient-centred language they can be seen as a way of transferring costs and responsibilities onto patients and families (Coulter & Ellins 2006; Morden et al. 2012). Indeed it has been suggested they resonate with an underlying policy imperative of individuals having a moral responsibility to look after their health and be empowered, 'activated' patients and 'good' citizens even though some will lack the skills, ability, resources or motivation to do this and may also face social and material barriers (Kendall et al 2011; Brooks et al 2015; Dwarswaard et al 2015; Foss et al 2015; Moore et al 2015). Furthermore it has been noted that professionals' understandings of self-care and self-management are based on a model of compliance rather than empowerment (Sawyer and Aroni 2005; Sadler et al. 2014; Dwarswaard et al 2015). A common criticism is that self-care and self-management tend to focus on the individual and changing their behaviour; neglecting not only their social context and lay understandings of long-term illness but also the influence and roles played by families and social networks (Rosland and Piette 2010; Audulv 2013; Ong et al 2014; Sadler et al 2014; Dwarswaard et al 2015; Miller et al 2015). This is particularly pertinent in relation to children/young people as parents play an important role in self-management/care and peers exert an influence over beliefs and behaviours.

Self-care and self-management

Although the terms self-care and self-management are used interchangeably in the literature distinctions can be made between them. Self-care is generally used in relation to both health promotion and long-term condition management whereas self-management is associated more with the latter (Kirk et al 2010). Indeed it could be argued that self-management is a sub-category of self-care. A body of research has examined what influences self-care/self-management and identified self-care/self-management activities and their underpinning behaviours (Figures 1 and 2). In mental health research and practice the terms 'self-care' and 'self-management' have been used less frequently although 'recovery' (Gillard et al 2010; Brooks, Davidson) and 'self-help' (Prymachuk et al. 2014) can be seen as analogous approaches. Recovery similarly emphasises positive health and wellbeing, social networks, empowerment, partnership working and encourages a focus on strengths, positive coping and resilience (Gillard et al. 2010; Leamy et al 2011; Le Boutillier et al 2011).

In this paper we will use the term 'self-care' and we will examine the evidence about 'what works' in supporting self-care in relation to children/young people with physical and mental health conditions. This will be based on two studies that we have conducted that involved systematic reviews and empirical research (Kendal et al 2016; Kirk and Milnes, 2015; Kirk et al. 2010; 2012, 2013; Prymachuk et al. 2014). In this paper we summarise and synthesise the findings from these studies.

Self-care support

The aim of self-care support is to enable individuals to enhance their health in relation to three areas: medical management of their condition, carrying out usual roles and activities and managing the emotional impact of their condition (Lorig & Holman 2003). Although self-care support can be thought of as being part of 'routine' professional practice, it is often associated with particular programmes or interventions which may be facilitated by health care professionals, lay workers or peers. These programmes usually aim to develop individuals' confidence, knowledge and skills using a range of cognitive-behavioural strategies and information resources (Barlow et al 2002; Boger et al 2015). Skills developed include problem-solving and decision-making skills and skills to help individuals effectively use resources and communicate with professionals.

Self-care support can be provided in a range of different ways (e.g. information provision, skills training, support networks, professional education) and via a variety of platforms (e.g. devices and technologies, real and virtual networks) (Department of Health, 2005). They can be group or

individual-based; focus on particular conditions or be generic. They may be provided by the NHS or other organisations in the public, private and third sectors and may be lay-led (e.g. virtual/online support groups and networks). In relation to childhood long-term physical and mental health conditions a range of different interventions for children/young people and parents have been developed and evaluated by researchers (Kirk et al 2013).

What works? Evidence from Systematic Reviews

Our two systematic reviews evaluated self-care support interventions for children and young people with long-term physical and mental health conditions (Kirk et al. 2010, 2013; Prymachuk et al. 2014). They looked at the available international evidence from quantitative and qualitative studies with the aim of identifying what was effective in improving outcomes and their acceptability to children/young people, parents and health care professionals.

Details on the individual self-care interventions evaluated in the reviews are presented in Kirk et al. (2010, 2013) and Prymachuk et al. (2014). Interventions varied in relation to their:

- Theoretical basis (e.g. self regulation theory, social learning theory)
- Aims
- Target (children/young people only, parents only, children/young people and parents; family including siblings; professionals)
- Location (home/community, hospital, school, combination of locations)
- Leadership/facilitation (lay or professional)
- Mode of delivery (e.g. face-to-face, virtual, individual child/family, group-based)
- Focus (condition-specific or generic)

Our reviews found that there is evidence that self-care interventions can improve a range of outcomes (Kirk et al. 2010, 2013; Prymachuk et al. 2014). They can improve children's health in relation to areas such as lung function, glycaemic control and mental health symptoms (e.g. anxiety, depression) (Barrett et al 2004; Jan *et al.* 2007; Biegel et al 2009; Wade *et al.* 2009). Interventions may also enhance self-efficacy, self-esteem, knowledge/skills and quality of life though there is less evidence of this for children with mental health conditions (Pfiffner et al 1997; Cicutto *et al.* 2005; Franklin *et al.* 2006; Biegel et al 2009; Dobson et al 2010). The evidence for whether these

interventions reduce health service use is mixed with studies reporting both significant reductions and no reductions (Wesseldine *et al.* 1999; Flores *et al.* 2009).

Our review of interventions for children with mental health conditions found that interventions that focus on individual children/families are more effective than group-based interventions (Prymachuk *et al.* 2014). For physical health conditions group-based interventions were far more common and were found to improve health status and psychosocial wellbeing (Cicutto *et al.* 2005; Wade *et al.* 2009). Studies examining participants' views report that children/young people and parents value group-based approaches (either virtual or face-to-face) for providing social support and the opportunity to share experiences, information and strategies (Bruzzese *et al.* 2004; Trollvik and Servinsson, 2005; Garcia *et al.* 2010; Garraway *et al.* 2010).

Some interventions investigated used e-health methods for self-care support, for example, computer games, online support groups, mobile phone text messaging. In the review focusing on long-term physical health conditions these were associated with improvements in psycho-social wellbeing, health status and condition-related knowledge (Christian and D'Auria 2006; Franklin *et al.* 2006; Jan *et al.* 2007). It also appears from both reviews that these types of interventions are acceptable to young people/parents as they are accessible and have the ability to 'fit into' daily life (Carroll *et al.* 2007; Van der Meer *et al.* 2007; Coyle *et al.* 2009).

In relation to interventions for children/young people with mental health conditions it appeared that those delivered by generic professionals (e.g. general nurses, teachers) were as effective as those delivered by specialists (e.g. mental health nurses, clinical psychologists) (Prymachuk *et al.* 2014). This may relate to the use of manuals to promote standardisation in delivery or because it is the personal attributes and interpersonal skills of the professional rather than specialist training that is important. In both reviews the relationship with the facilitator and their interpersonal skills was seen as being important by children/young people and parents (Anderson, 1997; Trollvik and Severinsson 2005; Garcia *et al.* 2010; Gowers *et al.* 2010;). In the review of mental health interventions it appeared that greater contact time with the facilitator could be beneficial (Prymachuk *et al.* 2014). This could be because this provided more opportunity to develop a therapeutic alliance.

What Works: Evidence from Empirical Research

We conducted case studies of different types of self-care support programmes operating in the United Kingdom to identify their acceptability and effectiveness from the perspectives of children/young people, parents and the professionals/workers involved in their delivery. Information about the programmes we studied and the research participants are provided in Tables 1 and 2.

The two studies identified similar key components of effective and acceptable programmes. These were providing a sense of community, developing knowledge and skills, building independence and confidence and engaging children/young people (Figure 3) (Kirk et al. 2010; 2012; Prymachuk et al. 2014).

Figure 3: Key Components of Self-care Support

Providing a sense of community was seen as an important component for three reasons. Firstly, it enabled the exchange of knowledge, skills and information. Participants described how they benefitted from the sharing of experiential knowledge gained from living with the condition and self-care techniques that others had found helpful. Secondly peer support reduced a sense of isolation and feelings of difference. Before participating in the self-care support programme parents and

young people had often felt alone. Accessing the programme resulted in the realisation that there were others experiencing similar feelings and issues and the group was seen as a safe place where feelings could be expressed, shared and understood. Thirdly programmes had the potential to extend social networks. In some cases friendships developed through participation in the programme. However, some participants felt a sense of loss if these friendships ended when the programme finished. Some mental health programmes discouraged socialisation outside peer group meetings due to fears that uncontrolled peer support might trigger self-harm behaviours or problems with eating (Prymachuk et al. 2014; Kendal et al 2016). Participants noted that the acceptability of peer support depended on the individual and their preferences and readiness for this form of support.

Participants described the important role of programmes in developing their knowledge and understanding of their or their child's condition. This knowledge was acquired through formally provided sessions and as highlighted earlier from the sharing of experiential knowledge. This included knowledge of the condition itself, how it affected themselves or their child and the development of self-care skills. The latter often included practising skills in their everyday lives outside the programme setting. Some programmes also helped develop young people's communication skills to enable them to communicate more confidently and effectively with health care professionals and teachers.

Building young people's independence and self-confidence was seen as important component of self-care programmes directed at children/young people with physical health conditions. This was less explicit in the self-care support programmes directed at children/young people with mental health conditions though reducing dependence, improving self-esteem, increasing resilience were implied, if not explicit, aims of the programmes evaluated. Programmes could include activities to help children/young people manage their condition independently but in a supportive environment. Such activities could also increase parent's confidence in transferring self-care responsibilities to their children and thus increase their independence. For programmes focussing on physical health conditions, providing opportunities for children/young people to participate in challenging activities (e.g. abseiling) was seen as building their self-esteem and demonstrating to their parents their capabilities and appropriate limitation boundaries. In addition, peer support and feedback could enhance feelings of self-confidence.

The ability of programmes to engage children/young people was seen as a key component. Fundamentally programmes needed to be accessible and provided in an attractive physical environment appropriate to the target group. It was emphasised that any activities aimed at promoting self-care had to be perceived by children/young people as enjoyable as well as gender and age appropriate. Being 'young person friendly' encompassed using children's/young people's ways of communicating such as text messaging and online methods (Kirk and Milnes, 2015; Kendal et al 2016). The inter-personal skills of workers involved in the programmes was highlighted as being vital and the personal qualities emphasised were approachability, being non-judgemental, active listening, empathy, compassion and trustworthiness. In relation to mental health programmes giving children/young people individual time and attention appeared to be a valued characteristic.

Conclusions

We found substantial similarities between physical health and mental health self-care support programmes in relation to impact on outcomes and in terms of children/young people's and parents' views of these programmes. One difference that emerged was that programmes focussing on individual children or families may be more effective in improving mental health outcomes although children/young people with mental health problems still valued peer support. Other systematic reviews have similarly reported that self-management interventions for children/young people, including those using the internet, can improve a range of health outcomes (Stinson et al. 2009; Lindsay et al 2014).

It is important to note that the research included in our systematic reviews varied in terms of its quality. Many studies lacked a theoretical basis and clearly defined and robustly measured outcomes. Some studies used parents as proxies despite evidence that parents and children can assess outcomes differently (Upton *et al.* 2005; Palermo *et al.* 2008). Outcomes relating to psychosocial well-being, condition-related knowledge and health behaviour were less frequently measured, particularly in mental health studies, even though self-care support interventions are essentially psycho-educational in nature and these types of outcomes are likely to be valued by families. In general there has been a focus on trials with limited high quality research on children/young people's or parents' views about self-care support interventions. Moreover, children, young people and parents have often not been involved in intervention development or in identifying outcomes of importance to them. It is also often unclear whether interventions have been adapted for different age groups or whether cultural diversity has been taken into account.

Many interventions have an individual behaviour change focus although researchers are now beginning to consider using more comprehensive theories to build interventions such as socio-ecological theory and social network theory (Miller et al. 2015). In addition it was evident, particularly in the mental health review, that researchers had frequently tried to ensure consistency in intervention delivery usually by using manualised approaches. Whilst this is important in a research setting, it emphasises fidelity over acceptability thus neglecting the individuality of children, young people and families in terms of their needs, preferences, experiences and resources. Our reviews suggest that computer-based interventions are both effective and acceptable. The use of the internet and mobile technology for self-care support has increased rapidly in recent years due to its potential for providing low cost support without geographical and temporal barriers (Silva et al 2015). However, concerns have been raised about quality, safety and integration with wider health services (Hussain et al 2015).

Our empirical work identified a range of approaches that have been implemented in practice and we have examined their acceptability and effectiveness from the perspectives of children/young people, parents and the professionals/workers involved in their delivery. Whilst the findings cannot be generalised in a quantitative sense, the combined sample sizes (145 participants) are large for a study of this nature and are drawn from a range of different self-care support approaches. We acknowledge that the sample only includes participants who chose to access these services. Four key components of self-care programmes emerged from this research: providing a sense of community, promoting independence and confidence, developing knowledge and skills and engaging children/young people. These components are supported by the evidence from the systematic reviews, particularly in relation to physical health conditions (Table 3) and provide an underpinning framework for self-care programme development.

The majority of the self-care support interventions included in our reviews do not appear to have been subsequently implemented in clinical practice. In some cases this may be due to the interventions being too resource intensive to be feasible to provide in the health service or this may relate to well-recognised and long-standing barriers to translating research into practice (Squires et al 2011). Nevertheless self-care is an important area for nursing practice and one where nurses should play a leadership role.

Implications for Children's and Mental Health Nurses

Our research suggests that there are four key components to an effective and acceptable self-care programme; providing a sense of community, promoting independence and confidence, developing knowledge and skills and engaging children/young people. Knowledge of these key components can be used by nurses and researchers in the development and delivery of self-care support programmes for children and young people with long-term physical and mental health conditions.

There are significant opportunities for nurses to support self-care in children and young people, not just in routine clinical practice but also in its promotion and in the potential to collaborate with others involved in its delivery. In our studies, many of the self-care support programmes were delivered by third sector organisations or by non-health professionals (such as teachers and youth workers) with little or no linkage to health services or health professionals. Nurses working with children and young people would benefit from broadening their networks to ensure that they are engaging and working with all professionals and non-professionals (and this includes children and young people and their parents and caregivers) who have a stake in promoting and supporting the physical and mental health of children and young people.

In terms of the direct delivery of care for children and young people with physical and mental health conditions, there are opportunities for nurses to integrate self-care support into routine clinical care and to include self-care support programmes in care pathways. Doing so should increase the uptake and availability of these programmes.

More fundamentally, the values, attitudes, knowledge and skills necessary to support self-care need to be incorporated within professional practice and pre-qualifying education programmes. The Department of Health's (2008) core principles for supporting self-care provide a useful framework for developing practice and education (Figure 4). According to this framework, nurses need to have the skills and knowledge to be able to: communicate effectively; identify people's strengths and abilities; provide advice on support networks; promote choice and independence; enable people to manage identified risks; and provide relevant and evidence-based information.

Finally, nurses need to understand that the UK, like much of the developed world, is facing a future where health service utilisation will be dominated by those with long-term physical and mental health conditions (NHS England, 2014). In this context, providing support for self-care and self-management is intrinsic to government plans for transforming future health care, not only because of the significant cost savings but also because self-care approaches embrace empowerment and

partnership. Nurses are ideally placed to be at the forefront of these transformations; indeed, nurses enabling healthy lives and supporting children/young people and their families to self-care is one of the cornerstones of the proposed changes to registered nurse education and training advocated in Lord Willis' *Shape of Caring* review (Health Education England, 2015).

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Figure 1: Influences on Self-Care/Self-Management (Bower et al 2009; Grey et al 2015)

Figure 2: Self-Care and Self-Management Activities and Behaviours (Lorig et al 2001,2003)

Table 1: Key Characteristics of the Self-care Support Programmes (n=12)

Characteristics	Residential camps	ADHD Group	Structured self-management programme	Online support group	Diabetes Team	Support Team	Self-harm Psycho-therapy Group	Dina School (Incredible Years)	Parenting Programme	Resilience Focussed Family Support	Online support group	Supported online CBT
Theoretical or philosophical basis	Self-efficacy Social support	Empowerment Self-efficacy	Self-efficacy Empowerment	Social support	None identified	None identified	Group psychotherapy, CBT, DBT.	Social Learning Theory	Social Learning Theory	Resilience, solution focus	Recovery	CBT
Target	CYP aged 6-17)	CYP aged 5-18 Parents/carers Professionals	Young people aged 12-18	CYP Parents (separate groups)	CYP up to 18years Parents	CYP up to 18 years Parents	YP aged 14-17; parents	Children aged 5-6 years	Parents of children aged 2-4 years	C/YP (5-14 years); Parents	YP up to 25 years	YP 14-30 years
Location	Community National coverage	Community Local area coverage	Community National coverage	Home National coverage	Hospital Home Community Local area coverage	Home Community Local area coverage	Hospital Local area coverage	School Local area coverage	Community Local area coverage	Home, community, school Local area coverage	Online National coverage	Community Local area coverage
Leadership	Third sector Lay volunteers and HCPs One paid manager per camp	Third sector. Lay volunteers and paid workers.	Third sector Lay facilitators aged 15-25	Third sector. Moderation only.	NHS Professionals Some parent volunteers.	NHS Professionals (Clinical Nurse Specialists, general nurses and a Social Worker)	NHS	Local authority and NHS	Third sector	Third sector	Third sector	Third sector
Focus	Asthma	ADHD	Generic	CF	Diabetes	Generic	Self-harm	Emerging behaviour or emotional problems	Behaviour problems	Behaviour problems	Eating disorder	Depression and anxiety
Medium	Face-to-face in a holiday location	Face-to-face groups (discussion, activities) in community centre. Separate groups for parents and children, activity programme for YPs.	Face-to-face groups (discussion, activities) in non-NHS locations.	Online peer support via discussion groups	Face-to-face groups (discussion, activities) in community and hospital settings; residential holidays	Face-to-face home based support and telephone advice for individual families; trips for children and siblings.	Face-to-face groups	Face-to-face groups	Face-to-face groups	Face-to-face individual support	Online peer support via discussion groups	Face-to-face individual support and guided online CBT.

Table 2: Sample Characteristics (n= 145)

Participant Group	Number	Percentage
Children and Young People ¹	43	29.7
Parents ²	47	32.4
Professionals/workers	55	37.9

¹Aged 5 to 18 years; 25 male, 18 female

²39 mothers, 8 fathers

Table 3: Relationships Between Key Components of Self-care Support and Systematic Review Evidence

Key Component of Self-Care Support	Evidence from Systematic Reviews
Providing a sense of community	Group-based interventions - improve health status, psychosocial wellbeing. Mental health conditions - interventions that focus on individual children/families are more effective than group-based interventions in reducing symptoms. Group-based approaches (either virtual or face-to-face) valued for providing social support and the opportunity to share experiences, information and strategies
Promoting independence and confidence	Self-care interventions can improve self-efficacy
Developing knowledge and skills	Self-care interventions can improve condition-related knowledge
Engaging children/young people	Ehealth methods for self-care support (computer games, online support groups, mobile phone text messaging) can improve psycho-social wellbeing, health status and condition-related knowledge. They are seen acceptable delivery methods due to accessibility and ability to 'fit into' daily life. Relationship with facilitator and their interpersonal skills are important for children, young people and parents. Greater contact time with facilitator can lead to improved outcomes for children/young people with mental health conditions.

Figure 4: Core Principles for Nursing in Supporting Self-Care (adapted from DH Core Principles to Support Self-Care, 2008)

Ensure individuals are able to make informed choices to manage their self-care needs.

- Practice is informed by the principles of respect, dignity, choice and independence for individuals.
- Nurses encourage and support individuals to make decisions
- Practice is based on values that support and empower individuals to be in control of their needs

Communicate effectively to enable individuals to assess their needs, and develop and gain confidence to self-care

- Nurses use communication and relationship skills to encourage and support individuals to work with them in identifying strengths and abilities; areas for development and to find solutions building on existing skills.

Support and enable individuals to access appropriate information to manage their self-care needs

- Nurses encourage and support individuals in accessing appropriate information and where possible provides the relevant and evidence based information in an appropriate manner, providing sufficient choice/options.

Support and enable individuals to develop skills in self-care

- Nurses facilitate access to appropriate training and self-care skills development within or outside their organisation in order to develop and support individuals' confidence and competence to self-care.
- The nurse also supports individuals in developing self-care skills

Support and enable individuals to use technology to support self-care

- Nurses ensure appropriate equipment, tools and devices are discussed and where appropriate provided
- Nurses engage with individuals to support and enable the use of technology

Advise individuals how to access support networks and participate in the planning, development and evaluation of services

- Nurses advise individuals about participation in support networks both to receive from and give support to others
- Nurses promote and encourage involvement of individuals in the planning, development and evaluation of services they receive.

Support and enable risk management and risk taking to maximise independence and choice

- Nurses encourage and support individuals to make choices about how to live their lives and manage any identified risks.
- Nurses promote choice and independence while supporting individuals to manage risks proportionately and realistically.