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Evaluation of a choir as a non-medical intervention for children with asthma:

BreathStars

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ABSTRACT

A shift in current health policy has seen heightened focus on non-medical interventions which can be delivered out with formal healthcare settings, to complement and enhance the clinical care of people with long-term conditions. Asthma is a common long-term condition managed by pharmacological and non-pharmacological interventions. Recent research activity has focused on the use of singing for respiratory health due to its similarity with the more well-known intervention of breathing exercises. The aim of this study was to determine if singing improved breathing in children with asthma. A realist evaluation study design with a mixed methods approach was adopted to evaluate a singing group for children aged 7-12. Results obtained through framework analysis of the data indicated notable improvement in asthma control with the added impact on self-esteem. Enjoyment of the singing group within a family centred approach was seen as a positive alongside the community benefit of wider asthma education. Lessons can be learnt from this evaluation which could inform future initiatives relevant to the current agenda of asset based approaches such as social prescribing within the context of the current devolution of the health and social care budget in the North West of England.

Keywords:

asthma; children; singing; impact; BreathStars Asset-based approach, social prescribing

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INTRODUCTION

Current treatment guidelines for the management of asthma in children and young people include pharmacological and non-pharmacological interventions (National Institute for Health and Care Excellence [NICE], 2017). Current non-pharmacological interventions include breathing exercises which can be offered as an adjuvant with pharmacological interventions such as short acting beta-antagonists and inhaled corticosteroids to reduce symptoms (British Thoracic Society and Scottish Intercollegiate Guidelines Network, 2016). Breathing exercises are used on the basis that asthma symptoms can be exacerbated by hyper-ventilation, though there are more effects. Thomas and Bruton (2014) suggest three purposes of breathing exercises: breathing retraining to improve breathing patterns; respiratory muscle training to enhance strength and endurance in respiratory muscles; and musculoskeletal training to improve posture through flexibility of the thoracic cage.

Studies on the use of breathing exercises in children with asthma have found that they are beneficial in reducing anxiety and improving lung function (Azab, Moawd and Abdul-Rahman, 2017; Chiang, Ma, Huang, Tseng and Hsueh, 2009). However, a Cochrane review completed by Macedo, Freitas, Chaves, Holloway and Mendonca (2016) suggests that conclusions on the effectiveness of breathing exercises could not be made due to the different approach and design of the studies. That the exercises were delivered as an adjuvant rather than stand-alone treatment was also a factor. However, breathing exercises can also have a positive impact on the quality of life of a person with asthma: a factor that was not appraised in the Cochrane review (British

Thoracic Society and Scottish Intercollegiate Guidelines Network, 2016; Macedo, Freitas, Chaves, Holloway and Mendonca 2016).

Singing has received recent research attention for respiratory conditions including chronic obstructive pulmonary disease (COPD), Cystic Fibrosis, Bronchiectasis and asthma (Lewis, Cave and Hopkinson, 2018; Irons, Kuipers and Petocz, 2013; Irons, Kenny and Chang, 2010). It is thought the breathing control used whilst singing is similar to that used in breathing exercises for asthma (Gick and Nicol, 2016). A review of the literature identified only two studies investigating the effectiveness of singing on asthma, with only one of these focusing exclusively on children (Eley, Gorman and Gately, 2010; Wade 2002). Both studies used quantitative methods to explore the use of singing in comparison with another intervention such as listening to music or playing an instrument on lung function and asthma symptoms. The findings from these studies included an improvement in health and wellbeing as well as the enjoyment of participating in the intervention.

There has been a fundamental shift in current health policy with a focus on new models of care encouraging integration of services, and a role for community and volunteer services through social prescribing (NHS England, 2014; Foot 2012). Social prescribing is seen as an asset-based approach, linking patients to services outside formal health care with the focus on the creation of health rather than prevention of illness; in particular, improving the health and well-being of people with long-term conditions (Marshall and Easton, 2018; Foot, 2012). There will be an increasing need to integrate the learning and the evidence from ventures using this approach to capture the outcomes within multiple contexts. An example is provided here of a novel initiative

which provides the opportunity to appraise both the potential and the challenges of this approach in the different context of children and families.

The aim of the example project was to test if singing improved the breathing of children with asthma through attending a group called BreathStars. BreathStars is a project based in the North West of England, managed by an entrepreneurial Registered Nurse with personal lived experience of asthma. She partnered with an established social enterprise and an internationally renowned music and arts organisation to ensure a musically robust, community-focused approach. A singing teacher and professional soprano experienced in singing for breathing worked alongside the nurse.

Children attended the group with their siblings and parents, offering different perspectives on how BreathStars had impacted on their breathing. External, independent evaluation was secured from the University of Salford, with all relevant data being made available. Access to BreathStars for additional data collection was arranged via the project manager. In line with research ethics, permission was obtained to name those involved in any research output. The evaluation had the following objectives:

1. To understand how the project made a difference to children, families and communities;
2. To understand any measurable differences, especially regarding time off school, visits to GP or accident & emergency department, and ability to enjoy a normal life (such as participating in games and physical activity);

3. To highlight any unintended consequences (positive or negative), such as the knowledge, understanding and support (or not) of family members and the wider community.

MATERIALS AND METHODS

Participants and Setting

Children aged 7-12 years old with a diagnosis of asthma were the focus of the project; a proxy indicator was the inclusion of an inhaled corticosteroid within their treatment regime. The location was selected for its high prevalence of asthma due to traffic pollution and its being in the worst 3% of areas of disadvantage in the national index of multiple deprivation (IMD).¹ Recruitment to the BreathStars group was initially through local schools, health services, and art and community organisations, all of which were visited individually by the project manager or the project volunteer. All schools and general practitioner (GP) surgeries in the local area were emailed about the project, and three school assemblies and one school gate engagement activity were conducted to encourage children to take part. Child-focused activities such as the use of puppetry and seasonal events were also used to engage with families at the local shopping centre to encourage recruitment. Social media and the local press were also used to recruit children and families to the project.

The children met weekly for an hour's singing initially at a local high school. BreathStars moved to a more central location (the local library) after the first term due to difficulties with families travelling to the original setting. Children and families enjoyed the library as well as the singing, with some siblings choosing to stay in the library and some joining in the group. Four children with asthma attended with their families. This increased to six after the move to the library, but then two children left. One family did not provide a reason, but travel may have been a factor as they lived

¹ <http://dclgapps.communities.gov.uk/imd/idmap.html>

outside the project area. The other child left during a period when a project volunteer rather than the project manager attended the group to lead the session.

Study Design

A realist evaluation approach was adopted in view of the context-bound nature of the planned outcomes. Realist evaluation is grounded in realism and is a theory-based approach to evaluation (Blamey and MacKenzie, 2007). Evaluative research is said to be concerned with the success or failure of a particular intervention, that is, how well things work, often resulting in inconclusive findings (Ritchie and Ormston, 2014; Blamey and MacKenzie, 2007). However, realist evaluation addresses the mechanisms by which outcomes are achieved and change is realised as well as the influence of context in producing those outcomes (Pawson and Manzano-Santaella, 2012). For this project, the emphasis was on learning from this initiative, a realist evaluation approach questions what worked well for whom, in what contexts, and how (Pawson and Tilly, 1997).

A mixed-methods design was adopted for this study to allow statistical analysis of what could be measured, with qualitative methods employed for those aspects which could not, such as impact of attending BreathStars on the child and family. Measurable data was collected from wall charts completed by the children about their asthma control. Responses to the Childhood Asthma Control Test (C-ACT) were also collected as measurable data. Qualitative data was collected via interviews which were conducted by the researchers with children with asthma, their siblings and parents using both audio- and video-recordings. This was supplemented with data from telephone interviews with other stakeholders. Postcards containing three questions captured

qualitative data from children, non-asthmatic siblings or friends, and parents about their experience of attending BreathStars.

The C-ACT is used for monitoring purposes to determine if symptoms including coughing and waking at night are well controlled (British Thoracic Society and Scottish Intercollegiate Guidelines Network, 2016). It was developed as a validated tool to assess asthma control and identify children with inadequately controlled asthma (Liu et al, 2007). In 2010 Liu et al established cut-off points for clinical application that corresponded with United States national guidelines for children aged 4 to 11. The C-ACT is interpreted such that a score of 19 or less means that asthma may not be well-controlled and more medical intervention could probably help. Scores of 12 or less suggest poorly controlled asthma and the need for active intervention. Acceptable control is indicated by scores of 20 or more. A key aspect of this instrument is that it encourages use by families, with initial, simple questions for the child and more difficult questions for the parent or carer. An online version is available in many countries and languages, and this reports an overall score, advising on seeking further medical intervention if indicated.

The control tests were completed twice within six months of the establishment of BreathStars. The purpose of the interviews was to discover the child's and family's thoughts, feelings and experiences of attending the group and the impact of this on their asthma control. Semi-structured interviews were used, taking into consideration the different ages and development stages of the participants. Four questions were used as a guide to collect similar data from each participant but the sequencing of

these questions was inconsistent based on the responses received (Holloway and Galvin, 2017).

The varied nature of the data that was expected prompted the use of a framework analysis approach. This is a method which adds to the rigour of the research through the transparency of its analysis of the data thus enhancing the validity of the findings (Smith and Firth, 2011). The frame for this was set by the facets of the evaluation objectives, and according to identification of mechanisms, outcomes and context central to realist evaluation (Ritchie, Spencer and O'Connor, 2003). Problems with completion of the C-ACT and the wall charts limited the analysis that could be applied to this aspect of the data.

Ethical issues associated with the evaluation centred on ensuring that all involved understood what their involvement would entail, that participation was free from perceptions of coercion, that personal and study data were stored securely, and that personally identifying details were excluded from reports and publications. The children were invited to adopt a celebrity identity for themselves as a pseudonym. Approval was obtained from the University of Salford Research Ethics Committee (Ref HSR1718-080) prior to the evaluation of the project being undertaken.

RESULTS

Findings are presented according to the evaluation objectives with further categories identified within these.

1. How the project made a difference to children, families and communities

Asthmatic Control

While the quantitative measures were not able to detect statistically significant changes, both children and parents reported notable improvements in asthmatic control. Coughing was reduced for two children, particularly at night. One child was taking his Salbutamol inhaler less frequently and was out of breath less often. Another reported taking “the blue inhaler” (Salbutamol) as often as before, but only as a preventative rather than to abort an asthmatic attack. None reported wheezing so there was no change in this. Understandably, children and parents found it difficult to quantify the reported changes, but they were in no doubt as to the existence of the improvement.

Impact on the Family

Two children acknowledged that their sibling with asthma used to keep them awake or disturbed their sleep sometimes because of coughing, but this was less common since joining BreathStars. They felt less tired as a result. Two mothers who were interviewed reported having more time to spend on their other children since the child with asthma seemed to require less attention.

2. Measurable Differences in Asthma

The aspiration had been to review changes in indicators such as time off school, visits to GP or accident & emergency department, and ability to enjoy a normal life (such as participating in games and physical activity).

Compliance

Compliance with the measures was variable. The Child Asthma Control Test was completed more consistently than the wall chart asthma poster. However, neither was completed such as to provide rigorous data. With the limited number of participants, this was not an issue, but learning for further projects was clear. Part of the problem was failure to complete repeated measures. This is a perennial issue with self-completed diary-style instruments. One of the briefest and simplest instruments had been selected for use; the project had already adopted a time-sampling approach (one week of daily recording at three points in the project) which is known to improve compliance; and a fun, child-oriented wall-poster was provided. Though reported only by one parent, the task may have been subordinated in the daily routine of child care and forgotten, or may have been the impact of a child prevaricating until the task was forgotten.

Ideally, an electronic means of recording would be used with remote prompting if the task were not completed. This would require internet access and appropriate hardware which may well not be available to many in the communities targeted by the intervention. Phone calls as reminders may prove counter-productive and are often ineffective anyway since they are no guarantee of compliance. That the C-ACT was completed better suggests that adults may be more compliant than children, and this C-ACT data encompasses the detail in the wall chart. Perhaps the wall chart data is superfluous and could be amended to report only problematic episodes.

The second issue was that the reported data showed hardly any change. One child reported having had a cold which prompted a change in wall-poster score. The reporting period may have been too short to capture changes. Moreover, an essential feature of asthma is seasonal variation for individuals who respond differently to hot or cold, perennial allergens, and annual bouts of infections such as influenza. These pose major challenges to asthmatic control. It would not be possible to factor this into the project since too many variables would be at play. In the absence of a 12-months project timeline, time sampling for periods of low challenge to asthmatic control is probably necessary, but this risks minimal variation in symptoms.

Reported Measurable Impacts

No episodes of requiring time off school or additional visits to the GP were reported, but the parents who reported to the researchers explained that there had been none in a similar period before joining the choir. Again, this aspect of change is likely to be a long-term measure and beyond this project (though it could be applied again in future versions).

3. Unintended consequences

BreathStars as a Positive Experience

Detail from the postcards, supplemented by testament during interviews, evidenced that children (with and without asthma) and their parents all found participation in the choir to be a positive and enjoyable experience. The perspective from professional musicians was that the benefits often seen by music interventions - increased concentration and enhanced confidence - were to be seen in the children who joined

the choir. Both mothers who were interviewed confirmed this independently, one adding further personal detail of the change in her child. They also spoke of better general behaviour linked to raised mood. This they attributed to a general improvement in self-esteem, and the ability to join in both this and other activities with other children (which had previously seemed impossible).

Perceptions of Games and Activities

An integral part of the intervention was exercises and activities, presented as games, that help to improve the families' asthma knowledge and which addressed psychological issues of lack of self-esteem and confidence by envisioning children with asthma as heroes rather than victims. Despite explicit explanations during the weekly sessions, the children who were interviewed denied any therapeutic link with the games and activities. They reported these to be simply "fun games". One child who was not asthmatic wished for fewer games and more singing instead. This child would probably not have experienced any physiological effects from the breathing exercises, so these activities would have meant no more than games.

One mother had a different take on this for children who were affected directly by asthma. She described them as being carried away with the singing and activities, and forgetting about the focus on their asthma. They seemed to have moved beyond undertaking the activities for an explicit therapeutic reason to simply enjoying *being able* to take part in them. This is a positive outcome as the impact could be achieved without medicalisation of the games and activities. These would leave parents with additional strategies to use to help with regaining control of breathing, and especially

the forced expiration that is necessary to counter trapping of air in the lungs during episodes of exacerbation of asthma.

Crucial Factors in Acceptance of the Intervention

Speaking of both the singing and the activities, one mother emphasised the importance of this being a non-medical intervention, a community activity that was not linked to statutory or formal services. In discussion, she suggested that this was what members of this community would usually prefer, and that they were generally service-resistant. This nature was emphasised by the community location, the emphasis on enjoyment, and the camaraderie of the mothers. A once-in-a-lifetime trip to Bridgewater Hall was offered by The Hallé as an example of this bonding between families and the potential for ongoing peer-support.

Importance of the Family-Centred Approach

BreathStars had been organised on the basis of siblings, parents and friends of children with asthma being encouraged to join in both the singing and the activities. Both adults and children who were interviewed held this to be an important factor in the success of the choir. Unaffected siblings enjoyed the experience but also came to understand better what their affected sibling was experiencing and how they might respond more positively and helpfully in future. Parents saw this change in unaffected siblings, remarking on increased tolerance of both their sibling and other children with long-term conditions. One of the children thought that it was good for children of any age to be included, and this was echoed by a volunteer who remarked on the readiness of very young children (of 3-4 years) to learn from the intervention.

Potential for Wider Impact

The potential for generational change was also pondered by a volunteer who had joined in the choir. She saw the possibility of wider change through this and similar initiatives, as children gained confidence and aspiration, perhaps to consider alternative employment, careers and perspectives on life. This requires further investigation, but has clear links to the Salford City Council's Fuelling Ambitions Creatively Together (FACT) project designed to promote exactly these attributes in young people.

Community Benefit

A volunteer and her daughter indicated that there could be wider benefits for the community and society at large. They spoke of helping other children (and parents) to understand asthma better, and one child reported having helped other children at school to take their inhalers more effectively (despite not having asthma personally). An entry in the postcards by a parent also showed that they were thinking about the potential for children to "learn how to help themselves and others with asthma". This effect would be similar to that sought by campaigns for all adults (and latterly children and young people) to be competent in basic first aid, hands-only resuscitation, or recognition of someone struggling with a mental health issue. If the initiative were to be rolled out wider, and if this effect were to be evidenced again, it might need to be reviewed as a public health intervention as well as a local primary health intervention.

DISCUSSION

Limitations and Learning

The area in which the project was located was known to have particular cultural and demographic features which made recruitment and engagement difficult (Robertson et al, 2016). Families tend not to have the inclination or the means to travel far, and this, combined with a general lack of trust of external initiatives, made for a challenging experience from the start. However, due in part to the established presence in the area of the project manager, as well as relocation to a more central venue, it was possible to recruit families - partly on a rolling basis. Indeed, in the postcards, three entries urged the recruitment of “more people” while another recommended “Inviting more children so even more fun”.

Attrition from singing groups and brevity of initiatives had been a limitation with other studies identified in a review of the effect of singing on respiratory health (Gick and Nicol, 2016). Despite the difficulties with recruitment, the project continued for five months. Extensive marketing of the choir had been undertaken through every available avenue, but participating mothers stated that they knew of other mothers who expressed interest when told, but had otherwise no knowledge of the opportunity. Another study which explored the effect of playing a musical instrument on asthma collaborated successfully with primary schools within a town in the North West of England to recruit participants (Andrew, 2006). This approach to recruitment was suggested by one of the music experts, with the aim of focusing on one primary school in order that greater coherence might be achieved and critical mass established to realise the “buzz” from group achievement. This would also ensure that resources

produce a greater return. It would be likely that families would live locally enough for attendance to be easy, and many families would know each other. However, whether this would depart from the intended non-service oriented and informal community development ethos needs to be considered. Within the context of the project as an example of an asset-based approach, social prescribing occurs outside formal services; though links with NHS primary care services would be needed as a point for referral (Foot, 2012). Other stakeholders felt disappointed that local NHS organisations and GP practices had not played a more active role in identifying and recruiting participants. Identification by GP systems would be simple, and this could be supplemented by community children's nursing teams if NHS buy-in could be secured.

A Positive Experience

Problems with recruitment (and retention) of families had knock-on effects for the potential musical achievement in performing as a choir. However, those who participated found it to be a pleasant and fulfilling experience. What made it a positive experience was the joy of singing, learning new songs, joining in with other children and adults, and the incorporation of games and activities. These results concur with other studies into the effect of singing which found that enjoyment contributed to greater feelings of wellbeing with an improvement in quality of life (Wade 2002; Eley, Gorman and Gately, 2010; Gick and Nicol, 2016). A study by Irons, Kuipers and Petocz (2013) into the effects of singing on young people with cystic fibrosis found that 60% of participants reported an increase in self-esteem which linked with adherence to medication; low self-image correlated with low adherence. Similar results were seen by children attending BreathStars as the positive experience caused wider changes,

in the context of greater confidence, improved behaviour, and raised mood and self-esteem. Other factors which contributed to the positive experience was the establishment of the group in the locality, the informal atmosphere (with parents bringing in food to share, for example), and the family focus. Eley, Gorman and Gately's (2010) work supports these findings by attributing success of their initiative to parental and community support.

Improved Asthmatic Control

Improvement in asthmatic control was reported by children, siblings and parents, notably reduction in the need for inhalers, less coughing, and less disturbance during the night. These changes were not sufficient to be identified by the C-ACT instrument or the wall poster. Other studies have failed to capture statistical evidence that singing improves asthmatic control which limits its recommendation in practice (Wade 2002; Eley, Gorman and Gately, 2010; Silwka, Tomasz, Tynor and Nowobilski, 2014). However, the aim of this evaluation was to review what worked, for whom, and in what context, as opposed to the success or failure of the intervention (Pawson and Tilly, 1997).

Pressures on Participants

Despite the adoption of strategies to encourage compliance, serial completion of the instruments was patchy, and consequently the data was less useful than had been hoped for. It was clear that parent-completed data was more reliable than that by children (wall posters). This response must be interpreted against the background of parents with busy lives, often with several children, who were seen to be rushing off to the next commitment as the session ended. A study by Lewis, Cave and Hopkinson

(2018) evaluating the impact of singing on COPD encountered similar difficulties with non-completion of assessment forms; an absence of explanation for this was deemed a weakness of their work. While their devotion to the singing and activities (indeed to the group generally) was unquestionable, the pressures on those who remained in the group may serve as an insight into reasons for others not managing to include the choir in their diary. An alternative approach to data collection was offered by Andrew (2006) in a study of the effect of playing a woodwind instrument on asthma in which weekly diaries were collected by school health advisors during a face-to-face meeting. However, there was no information as to the rate of completion for the weekly diaries.

Parents seemed a little surprised to discover some of the impacts on their child that they had observed but not registered consciously previously. Making these impacts explicit might serve to boost retention in the group. Similarly, the benefits gained by asthmatic children from the activities might also need to be made explicit (and repeatedly).

Wider Community Impacts

Wider community impacts were reported - for example, the ability and willingness to help other children with asthma following the gaining of new knowledge and understanding through participating in BreathStars. Understanding of the new knowledge and appreciation of the corresponding ability to improve both one's own asthmatic control and that of others was essential to this wider impact. Henry (2013) highlights the importance of control and confidence for those individuals managing long-term health conditions such as asthma suggesting community partnerships help to develop this. In the case of BreathStars, the ability and confidence to control their

asthma developed from an internalisation of the learning, the creation of new knowledge, perhaps through the enjoyment that singing had brought. The local community was known to be resistant to formal services, highlighted in the interview data and by a previous study by Robertson et al (2016). The emphasis of this project was a community approach to a non-medical intervention which encouraged health and wellbeing, with the potential to enable individuals and the community to thrive (Marshall and Eason, 2018).

Overall conclusion

Current health policy is focused on salutogenesis with asset-based approaches such as social prescribing aligned with this. There are few examples of such approaches in the context of children with long-term conditions and their families. BreathStars was an example project of such an approach. The evaluation focused on learning from the project, the feasibility of the approach and which factors should be considered in future initiatives. There were lessons to learn from this evaluation with an emphasis on a non-pharmacological intervention which was enjoyable and which exerted positive impact on the children and families. The findings from this study could inform other diverse local projects created to complement and enhance the clinical care of children with long-term conditions and their families (Greater Manchester Combined Authority, 2017).

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DECLARATION OF INTEREST STATEMENT

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