Group clinics for young adults living with diabetes in an ethnically diverse, socioeconomically deprived population: mixed-methods evaluation

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

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Scientific summary

Background

In recent years, the National Institute for Health and Care Research (NIHR) has identified a need to generate an evidence base for the use of group clinics in chronic conditions and to do so commissioned research in this area, including this study. We developed our research to address unanswered questions related to the use of group clinics that had recently been highlighted in a NIHR-commissioned systematic review [Booth A, Cantrell A, Preston L, Chambers D, Goyder E. What is the evidence for the effectiveness, appropriateness and feasibility of group clinics for patients with chronic conditions? A systematic review. *Health Serv Deliv Res* 2015;**3**(46)]. Specifically, we sought to understand how the context and delivery of group clinics underpin their potential benefit, and whether or not they might benefit people, including those from ethnic minorities, with long-term conditions.

Our research aimed to explore the scope, feasibility, impact and potential scalability of group clinics for young adults with diabetes. Diabetes (of all types) is becoming more prevalent in young adults, with a disproportionate increase (driven by type 2 diabetes) in young adults from ethnic minorities. For a young adult living with diabetes, early adoption of self-management practices and achievement of good glycaemic control from diagnosis can significantly reduce the risk of lifetime complications, prevent early mortality and reduce costs for health services. However, young adults with diabetes report poor experience of care and dissatisfaction with the care that they receive, and poor engagement and attendance with routine care. Young adults experience high rates of distress related to their diabetes and have poor health outcomes from diabetes-related emergencies, high-risk pregnancies, mental health comorbidities and diabetes complications. We, therefore, aimed to develop and evaluate a new model of care using group clinics to understand whether or not it might help young adults living in ethnically diverse communities through improving the experience of, and engagement with, diabetes care. We also aimed to understand feasibility and contextual factors important for the implementation of a group clinic-based care model within the NHS. We also aimed to understand what research is needed in the future to evaluate whether or not the care model could improve clinical outcomes, and undertook comparative analyses of clinical outcomes to guide future at-scale study designs. More broadly, our research aimed to contribute new understanding and knowledge to NHS service redesign relevant to people from underserved groups and with long-term conditions.

Objectives

Our research had the following research questions:

- How and to what extent might an innovative, co-designed group clinic-based care model meet the complex health and social needs of young people with diabetes?
- Could a group approach help support diabetes self-management? If so, what can the experiences of participants, the functioning of the group and the wider context in which the new model takes place tell us about its mechanisms of action?
- What are the feasibility, acceptability, cost and impact on outcomes of introducing group clinics for their users and stakeholders? What is the organisational impact of this model to the NHS and other stakeholders?
- What would be the optimal size and study design of a cluster-randomised controlled study to evaluate the clinical benefit and cost-effectiveness of offering group clinics to young adults with diabetes? What other factors should be considered when planning such a randomised controlled trial (e.g. factors relating to patient characteristics, existing models of service delivery, acceptability and mechanisms of action of group clinics on clinical outcomes)?

Methods

We performed a realist review to synthesise findings from existing literature to understand how group clinics may work for young adults with diabetes and other complex needs. This detailed evidence synthesis followed the approach and standards of the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) to understand 'what works, for whom, under what circumstances' with regard to group clinics for young adults with diabetes.

We performed a scoping exercise using National Diabetes Audit data from the time period 2017–18 [NHS Digital. *National Diabetes Audit – Report 1 Care Processes and Treatment Targets 2017–18, Full Report*. URL: https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit/report-1-care-processes-and-treatment-targets-2017-18-full-report (accessed April 2022)] and a questionnaire of health-care professionals delivering care to young adults to understand the national context and existing use of group-based care models, including clinics and education.

We then co-designed, implemented and evaluated a new model of group clinic-based care for young adults with diabetes at two NHS hospitals. Our study was underpinned by theoretical ideas influencing intervention development, implementation and evaluation, and a participatory approach to the research process. We used the experience-based co-design toolkit to build and adapt a model of group-based diabetes care, involving young adults with diabetes, health-care professionals and other stakeholders. We recruited young adults with diabetes at two hospitals that would go on to host group clinics, and another two hospitals that would become comparator (control) sites. All sites represented populations that were more ethnically diverse and more socioeconomically deprived than national comparisons.

Evaluation of the group clinic model was primarily qualitative and was undertaken by an embedded researcher ('researcher-in-residence'), incorporating ethnographic observation, qualitative interviews and documents in the analysis. We also collected sociodemographic and clinical data from participants and their health records, as well as using validated instruments to assess diabetes distress and patient enablement after clinical consultation. Our quantitative analysis of these data was to inform the feasibility and design of future evaluations at scale. We undertook a costs analysis (microcosting) to evaluate the economic cost of the group clinic model to the NHS.

Results

Our realist review highlighted four main principles that are important for the contextualisation and design of group clinics if they are to support engagement from young people: an emphasis on self-management as practical knowledge; the development of a sense of affinity between patients; the provision of safe, developmentally appropriate care; and a need to balance group and individual needs. Our review also identified that the implementation of group clinics within health systems was rarely, if ever, straightforward, and required numerous adjustments to existing operational and clinical processes. Furthermore, there was substantial 'hidden' work involved in delivering the new care model. Finally, it was noted that group clinics worked in addition to individual care, and that there was no evidence to suggest that group clinics offer a means to replace it.

Our analysis of National Diabetes Audit data confirmed the urgent need to improve care (and outcomes) for young adults, demonstrating that fewer than one in five young adults with diabetes meet nationally benchmarked targets for care process checks and treatment targets.

Through co-design, we built a model of group-based care to be delivered in existing clinical services that included young adults with all types of diabetes brought together in a non-judgemental and safe space, and who had been made aware of the purpose and intent of each session. The group clinics were facilitated by an experienced diabetes specialist nurse and youth worker, with other professionals brought in to lead themed group clinics on predefined topics when relevant. Staff were given training in facilitation skills. Co-design suggested the need for flexibility around the design and delivery of the group clinics, and identified that there would be challenges to the sustainability of the model in existing NHS structures. Co-design continued during the implementation of the group clinics, to allow for adaptation and improvement of the care model.

We recruited 135 young adults with diabetes from ethnically diverse backgrounds across our four study sites, the majority of whom had type 1 diabetes. Fewer than one-third of participants had received structured education previously. Group clinics were delivered at two study sites, with iteration and development to the model occurring over time. Overall, attendance was low, with 32% and 33% attendance per group clinic session at our two study sites. We refined and developed our approach to inviting young adults to group clinics, including involving a youth worker, and we adapted the model to incorporate service developments. As more group clinics were delivered, we noted repeated attendance from a core group of young adults.

Our qualitative analysis revealed positive experiences with group clinic care received by young adults with diabetes in this study. In particular, the ability to share an understanding of diabetes and normalise experiences with other young adults with diabetes led to feelings of being supported. The situated, social learning that came about from the groups and the facilitatory approach used by the health-care professionals delivering them was also favoured. However, both the young adults and the health-care professionals noted the extra work required in joining a new model of care, including the need to negotiate new roles and relationships, the potential for confrontation and altered power dynamics within groups. Unexpectedly, the diversity of attendees within the groups (e.g. the inclusion of young adults with both type 1 and type 2 diabetes) was mostly seen as a positive factor, expanding the opportunities for learning and sharing experience. Group clinics incorporated educational content, support of self-management and the delivery of care, but delivery of care was seen as more of a challenge because it was felt to require a greater individual focus than could be supported in a group setting. Some group clinics focused heavily on the delivery of care, but the majority focused on supporting self-management and education. The ability to receive one-to-one care in addition to group-based care was considered important to all those involved, and was perceived as something that could augment individual care and provide flexible, multidimensional care, support and education. The delivery of group clinics within an existing model of care based around one-to-one appointments was challenging, in part owing to the need to recruit individual patients and follow formal research processes, and also because of the amount of hidden work required to deliver group clinics and engage the young adults with them. However, the group clinics were flexible and adaptive and accommodated wider service developments. What evolved over time was an understanding that group and one-to-one clinical care fulfilled some different purposes, but that the two worked synergistically in delivering a model that could better meet the wider needs of young people with diabetes. Existing staff were critical to the delivery of group clinics, and the role of the youth worker was highly supportive of this, notably in engaging young adults and providing a facilitatory and developmentally appropriate approach.

We had significant challenges in obtaining quantitative data in this study, despite significant efforts to do so, and this has major relevance to the design of future, definitive research. These challenges were multifactorial and represent the complexity of working within a clinical environment with a high turnover of patients and non-attendance rates, and the likely unacceptability of the research process in this patient group. We also observed the challenge of the research process across multiple clinical sites with varied research support infrastructure and experience and, ultimately, our data collection approach was unfeasible. Our limited analysis of quantitative data showed no major effects (positive or negative) between young adults who attended and young adults who did not attend group clinics at the group clinic sites, except for some marginal improvement in a marker of patient enablement at one of the two group clinic hospital sites. Although these comparisons provide an interesting preliminary indication of the potential impact of group clinics, it, is important to reiterate that our quantitative analysis was not designed to provide a definitive evaluation of differences in clinical outcomes.

The average cost of delivering each clinic was £195 and £199 at our two sites. The average cost of group clinics per participant was £127–58, which is equivalent to the national cost of consultation with a diabetes specialist (£144) or emergency department attendance (£137). On average, study participants had 3.5 unscheduled contacts per year with health-care specialists (diabetes specialist nurse, general practitioner or practice nurse), at an average cost of £243. Our study suggests that group clinics would be good value for money if they prevent at least one unscheduled consultation per year. This observation should be taken forward in future randomised controlled trials in this area, with consideration of use of unscheduled health care as an outcome measure.

Conclusions

Our research engaged with young adults from ethnically diverse communities who were living with diabetes, and involved them and health-care professionals in the co-design of a new model of care based on group clinics. Using a theory- and evidence-informed approach to address our first two research questions, we identified that group clinics offered a foundation on which to improve care of their participants through the support of lasting and constructive relationships among young adults with diabetes, and between them and the clinical staff delivering care. Attendees at the co-designed group clinics found that they met their emotional care needs in a way that existing one-to-one care did not, and the social learning was helpful for young adults to learn or re-learn practical self-management. However, group clinics did not appeal to all young adults, and attendance at them was low. When young adults did attend, they found them helpful as a means to augment their existing care.

With regard to the organisational impact of group clinics, which was addressed in our third research question, we found that delivering care in group clinics offered both opportunities and challenges to staff. With appropriate training and support, staff were able to respond well to the needs of group clinic participants. The economic costs of delivering group clinics were not high, but were additional to routine care, and should be subject to future evaluation.

We anticipate that group clinics have the potential to become part of a future blended model of care for young adults in the NHS that incorporates both one-to-one care and group care. However, further research is required to develop the theoretical 'core' of a group clinic model (e.g. in identifying a way to assure minimum viable attendance) before it is ready for more empirical testing in a cluster randomised trial. Future research design should incorporate a new focus on digital and online approaches to engagement and delivery, and should minimise the research process as much as possible. For these reasons, we could not determine the optimal size or study design of a definitive trial, as we had set out to do in our objectives.

Our work did identify additional challenges to future randomised controlled trials with regard to the design of quantitative outcome measures. However, we determined that the use of existing data infrastructures, such as the National Diabetes Audit, to study outcomes would offer a potential solution to these challenges. Our finding that group clinics were able to support emotional care indicates the need for further study of psychological outcomes in future research. Future health economic evaluations could be guided by our finding that group clinics would be good value for money if they prevent at least one unscheduled health-care consultation per year. The design of a future cluster randomised trial to determine the effectiveness of group clinics on clinical outcomes would be challenging owing to logistical challenges in the NHS of delivering a blended, flexible model of care integrating one-to-one and group-based care, as well as considerable variation in how existing services are delivered.

Study registration

This study is registered as PROSPERO CRD42017058726 and ISRCTN83599025.

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