

Do youth workers have a role in improving diabetes transition services?

Satish Hulikere, Seth Jamieson

This article discusses the role of youth workers in helping young people with diabetes during their transition into adulthood. The informal nature of the relationship between youth workers and young adults, compared to those formed with formal diabetic services employees, has been qualitatively shown to improve sexual, recreational, personal and social needs of people with diabetes transitioning from youth to adult care. Furthermore, serious acute and chronic complications of diabetes were considerably improved by youth workers, as evidenced by reduced hospital admission and average HbA_{1c} levels.

Youth work is broadly defined as a service catering to the personal and social developmental needs of people aged 11–25 years (Watson, 2004). Youth workers have been used sporadically by the NHS to serve those with various conditions. Among all types of youth work, paediatric mental health services are most consistently used (National Youth Agency, 2019). Youth workers have been employed in paediatric multidisciplinary teams (MDT) to assist with the management of children and young people with long-term conditions, including diabetes. Both internationally and in the UK, healthcare providers who employ paediatric diabetes youth workers have reported improved outcomes in many patients (Bowen et al, 2010). This report examines whether the use of youth workers may be expanded to address challenges facing young people with diabetes.

Role of youth work in diabetes care Youth work in paediatric diabetes services

The literature suggests that young people often feel uncomfortable contacting their nurses or doctors about issues that they believe are trivial and are extremely conscious of wasting doctors' time, especially regarding mental health concerns

(Buschur et al, 2017). Barriers such as these have the potential to be reduced or eliminated by the informality of the relationship between a youth worker and the young person. Youth workers in healthcare improve treatment compliance, promote social engagement, ensures that children and young people feel heard, and generally improve the morale of children and young people with chronic or debilitating conditions. These benefits are generally considered to be caused by the informal nature of the patient-youth worker relationship (Radez et al, 2021).

Assessing the impact of employing a youth worker is difficult and the intervention can rarely be declared independent in the healthcare setting. There are, however, significant improvements in recognised baseline measurements that can be assumed to be a reliable indicator of the impact of employing a young worker. These measurements include the following: average HbA_{1c} as an indicator of chronic diabetes management, hospital admissions as an indicator of acute complications, and clinic attendance as an indicator of engagement with diabetes services. Other factors may be assessed using qualitative data, such as young people's opinions regarding their social and personal journey with diabetes, including

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Article points

1. Youth workers in healthcare improve treatment compliance, promote social engagement, ensures that children and young people feel heard, and generally improve the morale of children and young people with chronic or debilitating conditions.
2. The informal nature of the relationship between youth workers and young adults, compared to those formed with formal diabetic services employees, has been qualitatively shown to help people with diabetes transitioning from youth to adult care.

Key words

- Children and young people
- Transition
- Youth workers

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discussions regarding alcohol, smoking, drug use, and sexual health (Pyatak et al, 2014).

Challenges faced during diabetes transition

Diabetes transition refers to the time during which a young person moves from paediatric to adult diabetes services (Marshall and Waring, 2021). This transitional period is one of the most challenging of a patient's life. Approximately, 65% of the transition occurs when patients are aged 17 and 18 years. Young people with type 1 diabetes experience deterioration in annual care process completion, difficulty achieving treatment targets, and increased rates of diabetic ketoacidosis (DKA) while transitioning from paediatric to adult services (NHS England, 2016).

During this critical period, young people fail to adequately engage in services that are available to them (NHS Digital, 2017). Regular contact with diabetes services and attending MDT diabetes clinics is crucial for achieving good diabetes management. It is often the case, however, that young adults do not prioritise diabetes care due to competing interests, psychosocial issues and participation in high-risk activities (Peters and Laffel, 2011). Only 30% of people with diabetes in England and Wales aged 18–25 years meet treatment targets annually (Zaidi, 2021). Transitioning from paediatric to adult diabetic care poses a variety of challenges; young people who transitioned into adult diabetic services are 2.5 times more likely to have suboptimal glycaemic control than those who remain in the care of paediatric services (Balfe, 2007; Nakhla et al, 2017).

While it is true that adolescence naturally increases insulin resistance, which inevitably challenges glycaemic control, the transition also occurs at a particularly turbulent time in the lives of many patients (Zaidi, 2021). For some, this is the first time that they are entirely responsible for their diet, and thus, glucose control. Additionally, young people who attend universities or move away from home during the transitional period are likely to increase alcohol and recreational drug consumption, which complicates glucose management (Balfe, 2007). A confluence of challenges and healthcare system barriers increase the risk of loss to follow-up and contribute to poor

health outcomes observed among young adults with type 1 diabetes (Pyatak et al, 2014).

The management of type 1 diabetes in adolescents and young adults transitioning from paediatric to adult care is fraught with several challenges. In the UK, there is variation in the quality of diabetes service provision, with inequalities and regional variations during and after the transition. Increasingly, care providers have focused on formally preparing young adults to meet challenges associated with their transition to adult care (Saul et al, 2022). The central principle of the presence of adult care teams using joint care approach is the formation of new professional relationships between young adults and their caregivers. By building these relationships on a strong foundation, maintaining the relationship after the transfer becomes sustainable (Zaidi, 2021).

Diabetes UK recommends that a transition service should have young people at its centre, be responsive to their needs, and be supported by expert healthcare professionals (Diabetes UK, 2018). Increased recognition by healthcare professionals regarding the importance of the transition of care in people with diabetes has resulted in substantial care improvements (Iyengar et al, 2019). Personal relationships with care providers are a key aspect of solving transitional care problems. These relationships can be improved by employing young workers capable of building informal relationships with young people, thus promoting attendance and interaction with adult diabetes care providers.

A systematic review in 2014 found that young people and their families were more satisfied with the service and improved their quality of life when there was an emphasis on flexible continuity (Rea, 2014). This explicitly summarises why youth workers are a great option for NHS trusts; they provide flexibility to young people while the excellent standard of care provided by formal diabetic services is maintained. Moreover, the nature of some of the transition dangers, especially those caused by recreational drug use, alcohol, psychological issues, and sexual/reproductive concerns, are often only frankly and openly discussed by young people who have a strong relationship with their care provider. Youth workers may be needed to facilitate the formation

of a strong relationship with adult diabetic services, thereby allowing for discussions surrounding these issues.

Opinions of young people

Research suggests that young adults are keen to discuss transition and are concerned about their continued care. Transition workers in the UK have made progress in answering the questions of young people via written material, appointments and streamlining transition-related changes in the healthcare system. It is thought, however, that the informal nature of youth worker and young person interactions may allow the young person to ask questions that they believe to be trivial to a care provider but are nonetheless a major individual concern (Nakhla et al, 2017).

The burden of mental illness among young people with diabetes is immense, with 25% experiencing emotional or psychological problems (Rea, 2014). Tragically, Bateman also notes that 76% of people with diabetes felt that they have not been offered emotional or psychological support when they needed it (Bateman, 2018).

Studies have consistently shown that youth workers promote social engagement among young people with chronic conditions and can act as an informal support system that many young people need when experiencing psychological or emotional strain (Buschur et al, 2017). Mental health is a fundamental component of the UK Diabetes Transition Service. Young people with diabetes are 20% more likely to develop an eating disorder than the general public. While these needs are unlikely to be addressed by youth workers, the workers will be able to identify those developing eating disorders and encourage them to seek help (Marshall and Waring, 2016).

Additionally, young people with anxiety and depression have noted symptomatic relief when they could interact with youth workers regarding the everyday issues they experience due to living with a chronic disease (Satish, 2022).

Scope of future research regarding the role of youth workers in diabetes care

Limited research has been published regarding the potential role of youth workers in transition care. The role of youth workers in the diabetes transition

should not be considered a complete solution to problems faced. Further research should be conducted to establish precisely how to maximise the impact of youth workers on transition care and consider alternative approaches for addressing needs that are not met by youth workers (Zaidi, 2021).

Research should be conducted across the UK since local community needs will differ; thus, the role of a youth worker may need to be tailored individually to maximise the level of trust each young person has in youth workers. We believe that as the employment of more youth workers in paediatric diabetes services occurs, outcomes and feedback from young people may be used to improve the role of youth workers in the diabetes transition. The employment of youth workers should complement other service improvements that adult diabetes services require during and after transition. The *Paediatric Diabetes Best Practice Tariff* (BPT) specification is designed to incentivise high-quality, cost-effective care and reduce variation between Trusts. Importantly, a 2023 update of the BPT considers some standards that should be applied after the transition. These have the potential to improve the quality of support among those receiving transitional and young adult diabetes services (Diabetes UK, 2012).

Limitations to this proposal

Recruitment and training are obvious limitations of the youth worker model for transitional diabetic care. Warrington and Halton had great success with their youth workers and were able to recruit high-quality candidates. However, national community youth worker roles are common and often unfulfilled. Diabetic youth workers must undergo extensive training to familiarise themselves with the complex nature of diabetic care (Satish, 2022). However, not all youth workers are consistently supported by their local paediatric team or are able to utilise the shared knowledge of their MDT. Challenges associated with working for youth with diabetes may make it difficult to hire and retain youth workers.

Conclusion

While more research is needed to clarify whether youth workers improve post-transition outcomes

for young people with diabetes, current research has provided strong evidence for making such a claim. The informal nature of the relationship between youth workers and young adults, compared to those formed with formal diabetic services employees, has been qualitatively shown to improve sexual, recreational, personal, and social needs of people with diabetes transitioning from youth to adult care. Furthermore, serious acute and chronic complications of diabetes were considerably improved by youth workers, as evidenced by reduced hospital admission and average HbA_{1c} levels. Examples set by NHS Trusts that established service specifications for the diabetes transition could serve as a framework for a new national model for diabetes transition care. ■

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