Title: Quality of care for young adults with Type 1 diabetes in Ireland: rural-urban differences and impacts of national austerity measures.

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Abstract

**Background:** This study investigates quality of care for young adults with Type 1 diabetes in Ireland (23-30 years of age).

**Methods:** Semi-structured interviews with thirty-five young adults with diabetes and with thirteen healthcare professionals.

**Results:** Most interviewees (young adults and healthcare professionals) considered quality of care for young adults with diabetes in Ireland to be sub-optimal. Healthcare services for many young adults with diabetes were characterized by long waiting times, inadequate continuity of care, overreliance on junior doctors and inadequate professional-patient interaction times. Many services lacked funding for diabetes education programmes, for diabetes nurse specialists, for insulin pumps or for psychological support, though these services are important components of quality type 1 diabetes healthcare. Allied health services such as psychology, podiatry and dietician services appear to be underfunded in many parts of the country. While Irish diabetes services lacked funding prior to the recession, the economic decline in Ireland, and the subsequent austerity imposed on the Irish health service as a result of that decline, appears to be impacting them even further. A number of the young adults who took part in this study felt that they had to pay to gain access to basic diabetes services (such as opportunities to talk to Consultants or to get their feet examined); this suggests that good quality diabetes care in parts of Ireland may be becoming privatized in the face of austerity cuts. A number of healthcare services for young adults with diabetes appeared to be providing excellent quality of care; these services were mainly concentrated in large urban areas.

**Conclusion:** Good quality care appears to be unequally distributed throughout Ireland. National austerity measures appear to be negatively impacting health services for young adults with diabetes. There is a need for more Endocrinologist and diabetes nurse specialist posts to be funded in Ireland, as well as allied health professional posts.

**Keywords:** Type 1 diabetes; quality of care; young adult; emerging adult; Ireland.
Quality of care for young adults with Type 1 diabetes in Ireland: rural-urban differences and impacts of national austerity measures

Background

Young adults with Type 1 diabetes are a high-risk group [1] in that their diabetes control is often sub-optimal and they have an increased mortality risk compared to the general population [1,2,3,4]. Healthcare systems have responded to young adults’ risky health statuses by developing specialist services for them, for example specialist young adult clinics [3,4]). The aim of these services is to improve the quality of care that is offered to young adults with diabetes, thereby encouraging them to engage with health services and motivating them to improve their control. Although these services sometimes have mixed results, the importance of providing high quality care to young adults with diabetes is now widely recognized [4].

Most specialist services for young adults with diabetes focus on the first phase of young adulthood, that is young adults who are in their late teens and early twenties. This is considered to be the riskiest developmental period for young adults with diabetes [4,5]. Diabetes researchers also recognize, however, that there is a second phase of young adult development, broadly from about twenty-three to thirty years of age, where young adults experience a maturing sense of identity and begin to assume adult roles in society [6]. In general, specialist young adult services are not in-place for young adults in this age range (particularly those between twenty-five and thirty years of age). A substantial body of research has now investigated quality of care for young adults with diabetes who are in the first phase of young adulthood [7, 8]. However, little has been published on the quality of care that is offered to young adults with diabetes who are in the second phase, when specialist young adult services often stop working with them. This is despite the fact that the provision of good quality care during this period may have significant long-term benefits [4, 9].
Quality of diabetes care

The health services researcher Avedis Donabedian [10] proposed that quality of care was determined by three categories of factors: structure, process and outcome. Structure refers to the organizational characteristics of health systems, principally comprising two components: the healthcare workers who make up the system (e.g. numbers, professional types, their qualifications, etc.), and the physical materials and resources (facilities, equipment, money) and organisational structures through which they provide care [11, 12]. Process refers to all the actions that contribute to patient-care, and includes such concepts as continuity of care and the quality and quantity of interpersonal interactions between patients and professionals [10,11,12]. Outcomes refer to the effects of care on the health status of patients and patient populations [10]. Good quality healthcare is care that increases the likelihood of desired health outcomes [13], through being accessible [11]; safe, patient-centred and timely; and equitable (for example, it provides care that does not vary in quality because of geographic location, ability to pay etc.) [13].

A number of diabetes-specific quality of care guidelines have been developed, the most comprehensive of which are those of the American Diabetes Association [14]. The ADA’s recommendations stress the importance of people with diabetes having regular screening for eye, foot, and renal complications in addition to regular assessments of control through HbA1c measurements. They recommend that people with diabetes should have opportunities to participate in diabetes education programmes and should be screened for psychosocial distress. A number of authors have also developed quality of care guidelines for young adults with type 1 diabetes [1,4]. These guidelines state that professionals need to develop individualized care plans for young adults with diabetes, examine their psychosocial needs, assess their day-to-day barriers to diabetes management and establish continuity of care with them [1,9]. Healthcare professionals should ideally see young adults every three months [4].

Diabetes-related quality of care is usually measured quantitatively, for example by auditing biomedical outcomes such as HbA1c. However, the WHO 2000 quality of care framework points to the importance of asking patients about their views on the care they
receive [15], which is a prerequisite to undertaking quantitative measurements of the different dimensions of care that emerge in qualitative research, in larger representative samples.

**Type 1 diabetes care in the Irish health system**

Most type 1 diabetes care in Ireland is provided in public hospital clinics by a combination of nurses, junior doctors (doctors in training), and consultant doctors. Junior doctors rotate though posts in different hospitals as part of their training, and often do not yet have specialist training and experience in the treatment of patients with type 1 diabetes. While most consultants work in the public sector, many also work in private clinics where they see patients who generally have private health insurance. In response to severe economic difficulties [16] the Irish government has recently instated a recruitment embargo affecting public sector staff, which has meant that many medical and health-related jobs in the public sector are being left unfilled. Diabetes services are not immune to these cuts, and cost containment is now a key priority for Irish diabetes services [17].

While the cuts to Irish health services have been serious, the quality of care provided to public patients was questioned even before the recruitment embargo began. Writing in 2009, Evans et al. found that diabetes care in rural Ireland appeared to be provided to patients ‘in spite of the health system, rather than because of it’ [18]. People in Ireland often believe that individuals who pay to see Consultant’s privately receive priority over public patients (in what is often referred to as Ireland’s ‘two-tier system’) [19, 20, 21]. They also believe that private patients are more likely to be treated by Consultants, whereas public patients are more likely to be treated by junior doctors [19]. A significant proportion of the Irish population (estimated at 50% in 2009-10) pays for private health insurance in order to access what they perceive to be the benefits of the private system [19], although this proportion has been falling since the onset of the economic recession [22].

**Aims and scope of this research**
The present study aims to examine young adults’ (23-30 years of age) and healthcare professionals’ perceptions and experiences of quality of diabetes care in Ireland; to determine if regional differences exist in the quality of care that is provided to young adults with diabetes in Ireland; to explore perceptions around how the health insurance status impacts on access and care; and to examine if recent funding cuts to the Irish health system appear to be affecting health services for these young people. Previous studies that have examined quality of care for young adults with type 1 diabetes (of all ages) have tended to examine quality of care in limited settings or samples, e.g. patients from one young adult diabetes clinic [8, 23]. Only a handful of diabetes studies more generally have examined inter-regional or inter-setting differences in diabetes-related quality of care [24, 25]. We interviewed young adults with type 1 diabetes and diabetes healthcare professionals from a range of health services and settings around Ireland (see Methods), enabling us to capture a wide range of experiences of the quality of care available to young adults in this country. As well as highlighting the need for researchers and clinicians to pay attention to setting and regional differences in the care of young adults with diabetes, the study investigates how diabetes services for young adults are coping in an ‘age of austerity’, particularly in countries such as Ireland that have been severely affected by the ‘Great Recession’. The article argues for the need to adopt a broader health system perspective when examining quality of care for young people with diabetes.

**Methods**

We conducted forty-eight semi-structured interviews, thirty-five interviews with young adults with type 1 diabetes and thirteen with diabetes healthcare professionals (three endocrinologists and ten diabetes nurse specialists). The study was conducted in the Republic of Ireland. We recruited three young adults from a hospital setting in the Dublin
region of Ireland, and thirty-two via advertisements that we placed on Diabetes Ireland’s Facebook page. Young adults were eligible to take part in the study if they were between 23 and 30 years of age. The specific characteristics of the young adults who took part in the study are outlined in Table 1.

Our recruitment strategy enabled us to capture the perspectives of a range of young adults with diabetes from around Ireland. We sampled healthcare professionals to ensure that we captured the perspectives of both doctors and nurses, and professionals who worked in different hospital settings (general adult diabetes services vs. specialist young adult, rural vs. urban). Interviews with young adults usually lasted about an hour; interviews with healthcare professionals about twenty minutes. Ethical approval for the project was received from the Ethics committees of the Royal College of Surgeons in Ireland and from Beaumont Hospital in Dublin.

The first author conducted all interviews. All interviewees were provided with an information sheet and were asked to sign a consent form. A number of interviewees were interviewed over the telephone; these interviewees were asked for verbal consent. Interviewees were informed that the interview would be recorded and transcribed; after which the audio recording would be deleted. We offered each young adult who took part in the study a 20 euro gift voucher for their time.

The first and second authors thematically analyzed each of the interviews with the remaining authors commenting on their analysis and reviewing and contributing to the write-up. During the initial coding process the authors identified a number of micro-themes such as ‘long waiting times’, ‘geographical inequity’ and ‘lack of communication’. Once these themes were identified the authors searched the research literature for a conceptual framework that could encapsulate them. Donabedian’s quality of care framework was determined to be suitable. Most of the micro-themes that were identified by the authors could be fitted under Donabedian’s macro-concepts of ‘process’ and ‘structure’. A third macro-theme was identified through coding, ‘obtaining good

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1 Diabetes Ireland is the principle medical charity of individuals with diabetes in Ireland, the Irish equivalent of organizations such as Diabetes UK and the American Diabetes Association.
quality of care’. This theme does not fit neatly into Donabedian’s framework but could be explained as patients’ responses to structural and process-related problems in the Irish diabetes health system. These three major themes (process, structure, obtaining good quality care) became the organizing principles of the results section. We took care to identify negative or contradictory cases, and highlight them here where relevant.

<table>
<thead>
<tr>
<th></th>
<th>N (35)</th>
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<tbody>
<tr>
<td>Age (mean, SD)</td>
<td>26.9 (2.67)</td>
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<tr>
<td>Female</td>
<td>82.9%</td>
</tr>
<tr>
<td>No of years has diabetes (mean, SD)</td>
<td>11.5 (5.6)</td>
</tr>
<tr>
<td>A1C (mean, SD)</td>
<td>7.94 (0.76)</td>
</tr>
<tr>
<td>Number of blood tests per day (mean, SD)</td>
<td>4.47 (1.98)</td>
</tr>
<tr>
<td>On insulin pump (CSII)</td>
<td>25.7%</td>
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<td>Educated to degree level</td>
<td>93.9%</td>
</tr>
<tr>
<td>Private health insurance</td>
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</tr>
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Table 1. Demographic characteristics of young adults who took part in the study.

Findings

Overall

Most young adults and healthcare professionals considered quality of care for young adults with diabetes in Ireland to be unsatisfactory. A small number of healthcare services
for young adults with diabetes, however, appeared to be providing excellent quality of care; these services were mainly concentrated in large urban areas, particularly in Dublin. Good quality care therefore appeared to be unequally distributed throughout Ireland.

Services [for young adults with diabetes] are doing very poorly. (Nurse).

We’re talking about 20-30 year olds. I think the service we provide for type 1 patients, no matter what age they are, is completely suboptimal. (Consultant)

**Process issues in the public system**

As referred to by Donabedian, process refers to aspects of the health system that either directly impact upon or interact with patients. In this study three process related factors were identified: long waiting times, lack of communication between health services and patients and patient-professional interactions.

*Waiting times*

Just under half of young adult interviewees (n=16) described long waiting times to see diabetes professionals. These young adults generally felt that they waited longer now to see healthcare professionals compared to when they were younger. Waiting times of between six months and a year were common. There appeared to be two reasons for this. One was that interviewees sometimes attended specialist young adult clinics when they were in their late teens and early twenties, which placed a strong emphasis on seeing young adults on a regular basis. Most of the interviewees in this study had transitioned out of these clinics and into general adult diabetes services where waiting times were much longer. However other young adults who had been treated in adult services for a number of years reported that waiting times in these services had lengthened since 2008, which they attributed to funding cuts in the Irish health service as a result of government austerity measures and insufficient numbers of specialist diabetes staff.

At the start [when first diagnosed] the consultants were saying we want to see you back in three months, it might be a week or two weeks over. It wouldn’t be four
or five months over the date. I was told in May I had to go back in three months. My appointment was for this week and I got a call to say actually no, we’re cancelling you out of that clinic, we’ll see you in February. (Female, 28).

The waiting times were brutal. Sometimes they were so long I never actually got seen. It’s definitely got worse. (Female, 24).

We’re down a diabetes nurse [because of the national recruitment embargo]. So already our waiting list has gone out a bit longer than we would have liked. (Diabetes nurse specialist, rural hospital).

Several young adults felt that they were ‘cursed for being good’, by which they meant that they felt that healthcare services were less concerned about them and postponed their follow-up appointments because they had good control. These interviewees felt that Irish diabetes health services often followed a triage philosophy, putting most of their efforts and limited resources into patients with poor control. In contrast, they felt that patients with good control tended to be forgotten by the system because their needs were not as pressing. However they noted that the criteria that healthcare professionals often appeared to use to determine time investment in patients (biological markers such as HbA1c), and the frequency with which they saw patients, were somewhat flawed as patients could have good control but still experience diabetes-related problems such as psychosocial distress.

I would occasionally get the feeling that they probably aren’t as worried about someone like me so they tend not to have me in as much. They even said to me at one point they want me in a year rather than six months time. (Male, 28)

You might go in and the doctors are trying to catch up with the backlog and if you’ve got no issues they’re just like, ok, everything seems fine, I’ll see you in three months time. They’ve looked at one thing and that’s it, good luck. That can be quite frustrating. (Female, 30).
Long-waiting times were not limited to young diabetics seeking routine ‘check-ups’. A minority of interviewees (n=4) also described long-waiting times (up to a year) to be seen for urgent health problems such as blood vessel problems in their eyes.

I said I’m really ill, I said I need to see the Consultant… she told me I was going to be waiting 18 months (Female, 29).

The Consultant felt that I might have had a blood vessel problem and the only appointment they could give me was 8 or 9 months. (Female, 30).

Healthcare professionals agreed that young adults experienced long waiting times between appointments. However they also noted that some young adults contributed to this problem by not consistently turning up for their appointments and not calling clinics to reschedule. This meant that services were unable to reallocate these young adults’ time-slots to other patients and thereby reduce those patients’ waiting times. A number of young adults supported healthcare professionals’ assertions here.

I think it should also be highlighted that one of the factors that contribute to long waiting times is patients not coming to clinics. We usually have about 20-25% “no-shows” at our out-patients. (Consultant).

I presume there was an appointment and I cancelled or wasn’t able to make it which I’m guilty of doing occasionally. (Male, 27).

The reasons why some young adults in this study did not turn up for their appointments varied but were often at least partly time related. Young adults either felt that they did not have the time to go for their appointments (and particularly that they could not afford to take the time off work) or they felt that the appointments themselves were a ‘waste’ of time, for example because healthcare professionals would not have the time to discuss the issues that they wanted to discuss.
They say I can take x amount of hours out of my day whenever to come and sit in the hospital. Wrong. I can’t. I’m lucky enough to have a job and I want to keep it. I don’t want to be taking time off to come to the hospital. (Female, 30).

Because of the lack of resources and specialist staff in the Irish public diabetes system (see next section), if a young adult missed an appointment it was often difficult to rebook them back into the system within an appropriate timeframe. As described by young adults and healthcare professionals, there was very little flexibility in many Irish diabetes services.

I know with the young persons clinic if you miss one, the next one isn’t for another 6-12 months. Because the health service is so stretched it’s hard. (Female, 23).

Long-waiting times negatively influenced interviewees’ diabetes management in three ways. They prevented interviewees from obtaining important information that they needed, such as HbA1c scores, to fine-tune their diabetes control. HbA1c tests measure average blood sugar control over a three-month period. If the levels are tested yearly, then nine-months of blood sugar information will be lost. Lengthy gaps between appointments also undermined interviewees’ motivation to optimally manage their diabetes. Many young adults noted that their enthusiasm for managing their diabetes often increased significantly in the weeks preceding and succeeding their appointments. The longer that interviewees went between appointments, however, the more their enthusiasm tended to ebb, and the more they began to skip blood sugar recording, and neglect good eating practice. Thirdly the longer that young adults went between appointments, the more that they needed to discuss with healthcare professionals. This meant that when they finally did get to see a healthcare professional there was often insufficient little time to explore all of the items that needed to be talked about.

If you test HbA1c every six months means you’ve definitely lost something. You don’t know what was going on. They are not too concerned about that here (Male, 29).
For the first few weeks after clinic I’m all over it. But the longer you go between
appointments the more things tend to drop. (Female, 28).

When I go to clinic because it’s so long since I’ve been there it always falls to the
bottom of my lists of things to ask. (Female, 23).

*Lack of communication*

Health service communication with young adults outside of clinical appointments was
mixed. About half of young adult interviewees described good communication with
health services, saying that health services were easily contactable and followed-up with
young adults if they were experiencing difficulties with their diabetes. These services,
mostly located in urban teaching hospitals, sometimes allowed young adults to upload
their blood sugar results so that they could be provided with quick feedback. We
interviewed healthcare professionals from these services. These professionals were
satisfied with the service that they provided to young adults, but noted that providing
good quality telesupport of this kind was a significant resource burden for them. The
picture for the rest of the young adults, who were mainly from rural areas, was more
problematic. They described health services that had poor follow-up of patients and were
difficult to contact. Interviewees who did attempt to contact these services looking for
advice frequently received no response apart from the dial tone of an answering machine.
Responses, when they did come, often arrived weeks or months later.

If you leave a voicemail, half the time you won’t hear back. (Female, 26).

I’m sure any day now they’ll get in touch with me [sarcastic]. I’ve left messages
but it being the Irish health service, I don’t expect anything. (Female, 30).

*Interactions with healthcare professionals*
About two thirds of young adult interviewees described negative experiences with diabetes healthcare professionals. Complaints about short consultation periods were commonplace, with interviewees commonly seeing healthcare professionals for no more than ten or fifteen minutes every six months or once a year. This was obviously not enough time to explore young adults’ diabetes management concerns. Healthcare professionals themselves recognized that there was a significant problem here.

Instead of seeing type 1 patients four times a year, we’re seeing them one time, very brief amounts of time and that’s inappropriate. (Consultant).

A significant proportion of these young adults’ care appeared to be provided by junior doctors with 1-3 years of experience and registrars who were trainee specialists. These younger healthcare professionals were generally a source of frustration to interviewees. Interviewees felt that junior doctors did not know very much about diabetes, and that these doctors spent most of the consultation trying to learn from them (the patients). When junior doctors provided advice, it was generally considered to be generic and basic when interviewees wanted detailed, personalized advice. Junior doctors rotated quickly through clinics so there were continuity of care issues here as well. Interviewees rarely saw the same doctor from appointment to appointment. Interviewees were unified in their desire to see consultants for their clinical appointments, but it was often very difficult for them to access these senior professionals.

I think I have some young doctors which I work with and they seem to be learning a lot from the patients because I have quite a few years experience. So they seem to be learning a lot but they don’t give you a lot of input at the moment. (Male, 29).

I think that this whole going the hospital and meeting the registrars isn’t good. They just go “eat healthy”. I know that. It’s for their benefit rather than yours. They’re trying to learn from you. (Female, 23).
One of the major complaints that we seem to get at the support group is the waiting times at clinics and getting to see your consultant at the clinic. (Female, 30).

**Structure issues in the public system**

As referred to by Donabedian, structure refers to the organizational and systemic characteristics of health systems. Three structural related concerns were identified by this study: the inequitable geographical distribution of Irish diabetes health services, cost-containment pressures on diabetes services and cuts to Irish specialist diabetes staff numbers.

*Geographical inequity*

Diabetes services for young adults were considered by most interviewees (young adult and healthcare professionals) to be something of a postcode lottery. If young adults lived near a large University teaching hospital such as one in Dublin or Galway their probability of obtaining a good service was quite high.

I worked in Dublin and the services were great. (Female, 29).

There’s no comparison between the care here in Dublin and what I would have experienced down the country. They’ve dietitians and doctors and nurses here and I’m seen regularly. (Female, 30).

Young adults who lived outside of the catchment areas of these hospitals appeared to have a greater chance of receiving lesser quality of care.

I think if young adults can get into a specialty centre, I think it’s good. I think the service for anybody outside that small supply of good centres, I think it’s very poor. (Nurse, urban hospital).
Rural health services in particular often had a particular lack of a critical mass of specialist staff such as Endocrinologists. In some services nurses and more junior doctors were wholly responsible for young adults’ diabetes care, and these professionals could be dealing with hundreds if not thousands of patients (type 1 and type 2).

We deal with 3000 people with diabetes and there’s one nurse. (Nurse, rural hospital).

I’ve a friend who was a registrar somewhere down the country, one of the rural hospitals, her only knowledge of diabetes is she was the person who travelled with me for six months. She’d no training in it, no specific training and was left in a clinic to manage hundreds of diabetics on a given day. She thought it was crazy herself. (Female, 28- works as nurse).

Rural services were often under-resourced meaning that they were unable to offer the diabetes education programmes that their urban counterparts could. Additionally diabetes technologies such as continuous subcutaneous insulin infusions - CSII (insulin pumps) were mostly concentrated in urban clinics, meaning that young adults from outside these clinics’ catchment areas had fewer opportunities to obtain these devices. In order to obtain the best quality care a number of young adults from around Ireland were forced to attend diabetes clinics in Dublin, which meant that they spent significant time and money travelling to their appointments.

One of the biggest stumbling blocks we came up against was finding a structured education programme for type 1s. For a unit like ours that is minimally resourced we just don’t have that type of funding. It’s not that we don’t want to do it, we’d love to do it. A lot of the rural hospitals would be similar. (Nurse, rural hospital).

We also only get 12 insulin pumps a year and it’s not necessarily the young adult that get them. We get 12 for the whole of the west of Ireland [primarily rural region]. (Nurse, urban hospital).
Cost-containment pressures in the Irish system

A number of young adults felt that the Irish healthcare system was more concerned about providing them with the cheapest care rather than the best care. One young woman, for example, noted that auditors in the health system questioned her pharmacist to find out if she could be provided with fewer glucose test strips. A number of young adults also noted that pharmaceutical companies were beginning to fund functions that had previously been standard aspects of public sector care, such as glucometers and diabetes training programmes. About a quarter of young adult interviewees (including some from urban areas outside of Dublin) noted significant difficulties in obtaining diabetes technologies, particularly CSII (also referred to as ‘insulin pumps’) and when they were offered these devices they were not given a choice about the model they could take. They felt that the health system restricted their ability to obtain the most advanced CSII devices that, although more expensive, would give them the best quality of life. One young woman who attended an urban teaching hospital in Dublin, however, noted that her Consultant gave her a choice of three pump from which to choose from.

The chemist said do you need that many strips. I’m like, yeah. They’re like, there was a query about it. I’m hardly selling them on the street. (Female, 28).

You don’t get the best pump. You get the old one that costs less. (Female, 27).

It was money that was stopping my pump. It wasn’t the doctor or the nurses. I think they really do have a genuine concern. (Female, 26).

I was on the list for the diabetes programme for 18 months. They just don’t have the resources. It’s a pharmaceutical company that are paying for it now (Female, 30).

Healthcare professionals agreed that patients were often offered less expensive version of CSII but noted that many patients did well with such devices. One consultant noted that
some of the more expensive CSII devices were intended for individuals who are unaware of low blood sugars rather than for all patients with diabetes. There was a disjuncture here between Consultants and young adults, with young adults believing that they were being denied CSII devices on cost grounds and consultants feeling that the more expensive pumps were unnecessary for some patients. While acknowledging that cost-containment pressures in Irish diabetes health services were impacting on the care they could provide, consultant’s also noted positive aspects in that the health services still provided diabetic patients with free insulin, glucometers and diabetes-related medication.

Staffing issues
All interviewees felt that staffing problems –stemming from cuts in government funding– were an important cause of the process difficulties discussed previously.

It’s the constraints. They don’t have the money. I think it’s definitely money constraints. (Female, 26).

Many young adults described diabetes services using words such as ‘under-staffed’, ‘swamped’ and ‘struggling’.

One other thing I am aware of now in Ireland, unfortunately the hospital I’m going to for diabetes seems to be very understaffed. I get an appointment less than half the time that I got in the UK. (Male, 29).

I think due to budget cuts and stuff, staff started to get cut which was unfortunate but not their fault basically. (Female, 24).

Interviews with healthcare professionals indicated that diabetes healthcare services (both in urban and rural areas) often lacked sufficient numbers of consultant endocrinologists and diabetes nurse specialists (this is one of the reasons why young adults were likely to be treated by junior doctors). The lack of Endocrinologists in the system was felt to be a historical legacy of the underfunding of endocrinology services in Ireland. Consultants
noted that the numbers of endocrinologists in Ireland at the time that the study was conducted (2012) was significantly below international standards. Both young adults and healthcare professionals felt that health services that lacked Consultant Endocrinologists were at significant disadvantages.

The international and Irish recommendations is to have 5 to 6 Consultant diabetologists per 250,000 population. There is no service in Ireland that has anywhere near that number. Several hospital have only one and four out of the 51 public hospitals in Ireland have no Consultant at all. The lack of consultant endocrinologists is not due to the recruitment embargo per se, it is a reflection of the lack of resource of the profession over years and years unfortunately. (Consultant).

We’re in an unfortunate position at the moment in that our endocrinologist retired a year ago. We don’t have anybody long-term to drive the service forward. (Nurse)

The lack of diabetes nurse specialists in the system was also felt to stem from historical underfunding but was felt to be accentuated by recent cuts in funding as a result of the Irish government’s economic austerity programme.

The national embargo on public sector staff has affected the number of diabetes nurses. (Consultant).

A number of the nurses who we interviewed noted that diabetes nurses were not being replaced when they went on maternity leave – or were being replaced by less competent and less expensive non-specialist professionals, while at the same time services were dealing with increasing numbers of patients with type 2 diabetes.

If there’s people going on maternity leave or being out of work for whatever reason they’re not replaced by people who are competent. And that’s the
moratorium. These replacement professionals will make fewer referrals or you’ll have people like the dietitian picking up on referrals that should have been made eight weeks ago but weren’t because there were less experienced midwives in that weren’t really experienced with diabetes and wouldn’t have known the processes for referring. That’s definitely an issue. (Nurse).

Nurses felt that this problem - increased demand for diabetes services combined with a lack of capacity to meet that demand - has meant that specialist services for young adults with diabetes have begun to deteriorate in some parts of the country as the health system concentrates most of its limited human resources on older patients with type 2 diabetes.

Services [for Type 1 patients] have kind of deteriorated in that we have so many Type 2s coming in and no extra staff. (Diabetes nurse specialist, urban University hospital).

B There shouldn’t be the restrictions that we have to deal with.
A Is that because of the funding constraints in the health service?
B It is absolutely. We don’t have the manpower or the equipment (Diabetes nurse specialist).

There was also felt to be a significant lack of allied health professionals in the system.

I work as a dietician myself. Dietitian services are brutal. (Female, 28).

Psychological services for young adults were considered to be especially lacking. This was despite the fact that all healthcare professionals considered psychological support to be an essential component of care for young adults with diabetes. Even the best service usually only had a psychologist on call for less than six hours a week- and that time was needed to cover all of the patients (type 1 and type 2) that the service treated. Healthcare professionals felt that the lack of psychologists in the system meant that many young adults with depression and eating disorders were going undetected, and when they were
detected, untreated. Young adults who needed to see psychologists faced long-waiting times and the risk of being referred to different hospitals for treatment. Sometimes, if they were not at crisis point, they were forgotten. A number of nurses reported lobbying the Irish government for additional psychological resources, but noted that their entreaties fell on deaf ears.

A What’s your impression of psychological services?
B In Ireland?
A Yes.
B Oh awful. We have a psychologist six hours a week. It’s awful. (Nurse).

At the moment we miss psychological morbidity because, even if we do identify it, we send a referral and then it’s six months before they’re seen. (Consultant).

We’ve been writing for years to try and get psychology services in diabetes. That didn’t get us anywhere. (Nurse).

**Strategies for obtaining the best care in the Irish system**

This section describes the strategies that young adults used to obtain good quality care given the process and structure related issues outlined to this point.

A number of young adults (mainly those attending non-University teaching hospitals, or understaffed health services without Endocrinologists or diabetes nurse specialists) were upset and confused about the quality of care that they were offered.

The system is crazy (Female, 28).

It makes me so angry. And nothing but cuts all the time. It kind of worries me that if I did end up in hospital with diabetes…no way. Sorry. That scares me. (Female, 30).
Sadly from what I have seen over the last few years, HSE (Irish health service) cuts mean ever fewer rather than more services for diabetes patients (Female, 27).

Many of these young adults were worried that the public system did not care about them and would not look after them if they became seriously ill. Some felt that the only way to obtain good quality of care was to proactively obtain it. They used four principal strategies to do this. One was to pay for private health care (either out of their own pocket or by obtaining private health insurance). For the interviewees who chose to do so (and there were quite a number of them- see Table 1), going private had a number of advantages. It enabled them to bypass waiting lists. It gave them access to health services that could often only be obtained privately, such as psychological counselling or chiropody services. It also provided them direct access to consultants who they felt could provide them with better quality care and information than they would receive from junior doctors in the public system.

If we hadn’t gone privately we would have been waiting for another 2 or 3 years. (Female, 30).

The consultant in x felt that I might have had a blood vessel problem and, again if I had gone publicly, the only appointment they could give me was 8 or 9 months. So we said straight away we’d go privately so we went to the x and saw Dr. x there. He did all the tests, everything, photographs, pupil pressure and everything was normal. (Female, 30).

I think I rang the hospital and they told me the waiting list was 12 months. My mum made an appointment privately with Doctor X. She rang her secretary and was told if you go privately you can get into the public a lot easier. (Female, 28).

Young adults noted a number of disadvantages with the private system, however. The main disadvantage was expense. A number of young adults also felt guilty about using the private system. They felt that doing so was morally problematic and unfair because
other young adults did not have their resources. One interviewee who was considering purchasing private health insurance also described considerable struggles to find out what diabetes related costs were covered by different insurance plans.

I even felt bad about going private because that’s not really the way you should do things. (Female, 28).

A So if the hospital haven’t been doing foot exams are you going to see a chiropodist?
B When I can afford it I do and that hasn’t been for a while.
A How much do they cost?
B 60 euro. I think that’s something they should have. It’s part of our condition so why should we have to pay someone separately to do it. (Female, 28).

Ireland is full of a lot of shit and a lot of advertisement and at the end of it, what you get isn’t what they advertise. It’s very American unfortunately. (Male, 29).

The second strategy was to demand good quality care from healthcare providers. Many of the young adults who we interviewed felt that unassertive patients would be neglected by the health system. Young adults stressed the importance of demanding to see Consultants during appointments and of complaining to staff when they felt that they were receiving sub-standard care. In practice, however, interviewees often found it difficult to be this assertive. Some were worried about arguing with authority figures, others that if they complained they would be seen as ‘bad patients’ and healthcare professionals would punish them by providing them with lesser quality care. Embarrassment prevented a number of young adults from being assertive. Although young adults in this study were well in to their twenties, and some were around thirty, it was notable how frequently parents stepped in to advocate on behalf of their children.
Unless you actually say something they will forget about you. It’s crazy. Is it safe? No. It’s not. I started in the last year asking is the consultant here today, can I see him. I’m not leaving until I see him. Otherwise you could end up with a junior doctor…this sounds awful but just from working in the health service, and also from my own experience in clinics, if a doctor doesn’t like you, I don’t feel they have the same time for you. (Female, 26).

My mother keeps pushing my appointments every time she sees the Consultant. (Female, 27).

My mum actually made an appointment privately with Dr. X. I probably wouldn’t have done it on my own. It was my mum who made the appointment. I would have been very shy about doing it. I was almost annoyed that she had done it but she was actually right. (Female, 28).

The third strategy was to transfer to another clinic/diabetes service, which usually proved to be difficult. There was often no objective information that young adults could use to determine if one clinic was better than another. As a result young adults who were considering transferring were often forced to rely on rumors or recommendations from friends or colleagues. Most searched for information on the Internet and found that clinics’ websites were quite basic. Understandably a number of them were reluctant to move clinics, possibly to a worse clinic, on the basis of a rumor.

I asked around about reputations and which hospital to go to. In the end X hospital was really convenient. I had heard better things about Y hospital but you don’t know. There’s really nowhere to ask (Female, 27).

A fourth strategy that young adults used was to develop diabetes services for themselves where these services were not forthcoming from the public health system. For example, many young adults in this study wanted to receive emotional and social support to combat diabetes-related psychosocial distress. These young adults felt that the official
diabetes system did not provide them with either the quality or the quantity of the support that they needed, and as a result of this they began to develop their own young adult peer support networks.

When we went searching for support we couldn’t really see any out there so we said, let’s set one up on Facebook. It looked like if you want something done, do it yourself. (Female, 30).

We interviewed one young woman who established a peer support network. She felt that there was a great, and unmet, demand for peer support amongst young adults with type 1 diabetes. Acknowledging this fact she said that she went to her Consultant to find out whether the health system could provide her with additional (and fairly minimal) resources to extend the peer support group that she developed. Her Consultant was extremely enthusiastic about the idea, but said that the health system would not be able to fund it in any way.

I said to a consultant, ‘I know the Irish health system won’t want to know because it may cost money…’ He just laughed and was like, forget it. He said he can’t get what he needs and he is the hospital, not a support group. (Female, 30).
Discussion

Interpreting the results via the conceptual framework
Healthcare services for young adults with diabetes in Ireland have long been suboptimal, particularly in rural areas, a state of affairs that appears to stem at least in part from the historical underfunding of Irish diabetes services. This situation ameliorated somewhat in the ‘Celtic Tiger’ years as more money was pumped into the Irish health system, including into diabetes services. The economic collapse that Ireland suffered as a result of its banking crisis acted as an ‘external shock’ to the Irish health system [17], reducing funding again for structural aspects of diabetes care. Government austerity measures led to embargos on the recruitment of specialist diabetes staff and undermined health services’ abilities to provide young adults with resources that they could use to improve their care. Austerity cuts had particularly negative impacts on rural diabetes services with many of these services lacking structural funding for diabetes education programmes, for diabetes nurse specialists, for CSII or for psychological support, though these services are important components of quality type 1 diabetes healthcare (though many urban centres also lacked funding for these services, just to lesser extents) [4,14]. The structural issues identified here led to negative cascade effects in the health system, resulting in the problematic process issues that patients experienced such as long waiting times to see healthcare professionals, suboptimal interactions with these professionals when young adults finally got to meet them, and poor continuity of care. At the same time as austerity cuts were being implemented increasing numbers of patients with Type 2 diabetes were also coming into the Irish health system, which further reduced the time and increasingly limited resources that stretched health services could put into the care of young adults with type 1 diabetes.
Patients— including young adults in this study— responded to structural and process issues in the public health service by either attempting to develop their own services (i.e. support groups), by demanding care from professionals where they could do this or by seeking to escape into the private health care. Privatization of care may be acting in many parts of Ireland as an escape valve for public sector difficulties, in that private services are fulfilling what should be essential elements of a good quality public system for young adults with diabetes. Some young adults feel that they have to pay to gain access to basic services (such as an opportunity to talk to a consultant, to get their feet examined etc.), and that libertarian, market-orientated principles [26] are increasingly a feature of Irish diabetes health services. This raises major issues around equity, where good quality healthcare can be seen as a commodity to be purchased by those who can afford it in an ‘age of austerity’, rather than as a right, as was enshrined in Ireland’s 2001 national health policy ‘Quality and Fairness’ which said that every patient in Ireland should experience fair access to a high standard of treatment [21].

**Poor quality of care**

Overall, the study suggests that quality of care for many young adults with diabetes in Ireland in the second phase of young adulthood is problematic and is being undermined by government austerity measures. This is not to deny that there are some excellent individual diabetes health services for young adults in Ireland; however it appears that it is individual services that are excellent rather than the diabetes system as a whole, which is struggling to cope with both chronic (historical) and acute (post-2008 austerity) funding issues. The process-related problems that were identified are worrying as they indicate that many young adults with diabetes in Ireland are not experiencing patient-centre care (particularly those who live outside the catchment area of large University hospitals). This is of concern as patient-centered care helps to protect young adults with diabetes against negative outcomes, such as the risk of them dropping out of the health system [2]. The rural-urban inequity that was detected was also of concern, not least because geographic maldistribution of care is associated with poor outcomes in people with diabetes [27], and points to a phenomenon that has broader relevance internationally [28]. Bernard et al. [29] note that in an equitable system, resources should be equally
accessible to all patients. In Ireland, resources for young adults with diabetes are unequally distributed. Young adults outside of Dublin and other large urban regions such as Galway are at a significant disadvantage. This disadvantage is relative rather than absolute [30] (young adults outside of Dublin still have health services) but young adults attending rural services often lack access to health services and a critical mass of specialist staff vis-à-vis their urban counterparts. This is a failure to provide accessible care to all young adults, a core criteria for good quality of care [31]. It is also a significant missed opportunity [9] given that good quality of care delivered at this time of life may have significant benefits for individuals with Type 1 diabetes.

*Potential solution to the issues identified by this study*

Addressing the identified quality of care issues could be done in several ways. One would be to extend young adult clinics to all diabetes health services, and enable young adults up to thirty years of age to attend these clinics. Another would be to transfer the care of patients with type 2 diabetes to primary care, freeing up more specialized staff to work with patients with type 1 diabetes; alternatively the care of young adults with diabetes could itself be transferred to primary care healthcare professionals. A third would be to ensure that senior Endocrinologists take a hands-on supervisory role in the care of all young adults with diabetes.

The truth is that most of the responses needed require additional resources, in a state where further significant cuts to the national health budget are being demanded by international lenders [32]. For example, there is a need for more Endocrinologist, diabetes nurse and allied health professional posts to be funded; and staff salaries, in Ireland as elsewhere, represent the greatest cost (circa 70%) of the national health budget. Caught, as specialist diabetes services in Ireland are, ‘between a rock and a hard place’, national policy makers will be faced by the need to manage difficult trade-offs in the different dimensions of quality of care. There is clearly a need to provide a comprehensive range of specialist services to young adults with diabetes, as they transition out of early adulthood, which will conflict in a resource-shrinking health system with the need to ensure accessibility for those living in rural areas.
Strengths and limitations of the study

This is also one of the few studies of young adults with diabetes to examine quality of care for young adults with diabetes in the second phase of young adulthood, and one of the few studies to attempt to develop a national picture of quality of care for these individuals. The strengths of the study include a large qualitative sample and the inclusion of patients and professionals. The principle limitation of the study is that most of the young adult interviewees were recruited from the Facebook page of Diabetes Ireland. The young adults who joined this page were clearly highly educated (a higher proportion than in the general population) and may have been those with the strongest criticisms of the Irish health service, or at least the ability to articulate their criticisms (some studies of the Irish health system report that satisfaction with health services declines as education increases [20]).

Conclusion

This study investigated quality of care for young adults with diabetes in Ireland. It found that there were some excellent individual health services and diabetes-related policies in Ireland, such as the provision of free insulin and free diabetes medicine to young adult patients. However overall the findings are concerning and suggest that health system problems- accentuated by recent national austerity measures- are undermining quality of care for young adults with diabetes in Ireland. This will likely increase the risk of Irish young adults with diabetes experiencing negative long-term outcomes, with the attendant long-term cost-implications that will stem from such outcomes.

Competing interests

The authors declare that they have no competing interests.

Authors’ information

All authors were involved in the conceptualization and the design of the study. MB carried out the interviews. MB and FD analysed the interviews with SS, DS, RB and RC
commenting on their analysis. MB and FD drafted the manuscript and SS, DS, RB and RC revised it. All authors read and approved the final manuscript.

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