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Leaving Child and Adolescent Mental Health Services (CAMHS): the impact of diagnosis and medication management on optimal discharge or transition

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Abstract

Purpose: This study aims to explore how young people in child and adolescent mental health services (CAMHS) in the UK, Ireland, the Netherlands and Croatia, experienced leaving CAMHS and identified a range of factors impeding optimal discharge or transition to adult mental health services (AMHS). **Methods** Interviews about discharge or transition planning, including what information was provided about their ongoing mental health needs, undertaken with 34 young people aged 17-24, all previous or current attendees of CAMHS. Some interviews included accounts by parents or carers. Data were thematically analysed. **Findings:** A number of previously well-documented barriers to a well-delivered discharge or transition were noted. Two issues less frequently reported on were identified and further discussed; they are the provision of an adequately explained, timely and appropriately used diagnosis, and post-CAMHS medication management. Overall, planning processes for discharging or transitioning young people from CAMHS are often sub-optimal. Practice with regard to how and when young people are given a diagnosis and arrangements for the continuation of prescribed medication, appear to be areas requiring improvement. **Originality:** Study participants came from a large cohort involving a wide range of different services and health systems in the first pan-European study exploring the CAMHS to adult service interface. Two novel and infrequently discussed issues in the literature about young people's mental health transitions, diagnosis and medication management, were identified in this cohort and worthy of further study.

Keywords: Transition; mental health services; decision-making; diagnosis; medication.

Introduction

Adolescence is a time of increased risk for the onset of various mental health disorders, many of which continue into adulthood. Currently in Europe, most Child and Adolescent Mental Health Services (CAMHS) accept new referrals and provide treatment for young people until age 18. Beyond this age, young people with ongoing mental health needs must then transfer to adult mental health services (AMHS), primary care (including their GP) or voluntary sector services.

Research already describes a poor transition experience (Appleton *et al.*, 2021; Appleton *et al.*, 2019; Street *et al.*, 2018; McNicholas *et al.*, 2015). Furthermore, this period in a young person's life is often one of multiple and major changes, such as leaving school, moving away from home, starting employment and other moves towards greater autonomy, all of which can be challenging (Hovish *et al.*, 2012). For some young people, a paucity of adult services catering for their disorder, notably young people with Attention Deficit Hyperactivity Disorder (ADHD), compounds these challenges (Singh and Tuomainen, 2015; Young *et al.*, 2011; Taylor *et al.*, 2010). Thus, understanding the nature of these attitudinal and experiential barriers is of crucial importance to optimise informed decision-making by young people and to try and reduce the risks for premature service disengagement when specialist mental health services are considered necessary.

Both the academic research literature and national health policy and guidance, recognise the importance of early preparation and planning for transition, good communication and involving from the outset young people and where appropriate, their parents or carers. For example, this was highlighted in *Future in Mind* which set out the Department of Health and NHS England's vision for protecting and improving children and young people's mental health, (DH and NHS England, 2015). However, often this fails to happen in everyday practice (Broad *et al.*, 2017; Street *et al.*, 2018). Indeed, quite the opposite has been reported, with young people describing no preparation for, or involvement in any of the decision-making processes leading up to transition (Cleverley *et al.*, 2020).

Findings of a pan-Europe survey (Signorini *et al.*, 2018) provide valuable clues as to where some of the difficulties may lie. In the survey, 60% of the 28 countries reported that there was no specialised transition planning available in their country; 37% of countries noted no requirements to provide documented hand-over planning for transition, and initiatives such as joint working between CAMHS and AMHS, and/or partnership approaches involving the young person, were found to be either unavailable or to be very limited in the majority of countries. These researchers concluded that a lack of a connection between CAMHS and AMHS was the most commonly identified difficulty facing those needing transitional care.

MILESTONE, (Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe), an EU-funded project, aimed to improve transition between services (Tuomainen *et al.*, 2018). Eight countries (Belgium, Croatia, France, Germany, Ireland, Italy, the Netherlands and the United Kingdom) prospectively followed up a cohort of young people (N= 763) from 39 CAMHS as they approached the upper age transition boundary. Encompassing a randomised controlled trial nested within a longitudinal study, data were collected from young people themselves, their parents or carers and their clinicians via interviews and online questionnaires. These were administered at four time points (Baseline, 9, 15 and 24 months) to explore: clinical and health social functioning; the effectiveness of a managed transition intervention (Singh *et al.*, 2021) and via a number of different work packages, the financial/economic, training and ethical aspects of transition.

Data summarising the MILESTONE cohort profile (Gerritsen *et al.*, 2021) indicates that many of the cohort had serious mental health problems (on one of the scales used, the Clinical Global Impression Scale, CGI-S, 18.6% (N=142) were rated by their clinician as ‘markedly ill’, ‘severely ill’ or ‘among the most extremely ill’ in the week prior to being seen) and a quarter had reported trying to commit suicide (25.7%).

As part of the MILESTONE ethics work package, a series of qualitative interviews with 34 young people and 12 parents or carers from four of the partner countries (UK, Ireland, the Netherlands and Croatia) were undertaken. The aim of the research was to understand in-depth their experiences in CAMHS when approaching discharge or transition, including engaging with other services post-CAMHS and to explore any issues raising ethical concerns (e.g., understanding, involvement in decision-making and consent to care) identified by the

young people. In total, there were 41 interviews: 27 individual interviews with young people; 2 interviews with two young people; 3 interviews with the young person with a parent or carer and 9 with a parent/carer only.

These qualitative interviews are the subject of this paper. The focus is on the perspectives of the young people and analysis of the data relates to two issues which emerged and which have been less frequently raised in the 'CAMHS transition literature'. These are firstly, how young people experience receiving a mental health diagnosis and the somewhat contradictory issues and emotions this may evoke in terms of on one hand, wanting certainty and yet on the other, being worried about being labelled, pathologised or made to 'fit' within a certain diagnosis. The second is how their medication is managed as they move services. Both may have an important bearing on their readiness and preparation for moving services.

Other analysis of the data includes young people's experiences of mental health after reaching their 18th birthday and will be reported elsewhere. Throughout the paper, young people's experiences are illustrated through selected quotations, with the abbreviations UK, Ire, NL and C referring to the four participating countries. Approvals for the study were given by Research Ethics Committees in all four countries: by the St John of God Research Committee, Dublin, Ireland; the UK National Research Ethics Service (NRES Committee West Midlands, South Birmingham); the Klinicki Bolnicki Centar, Croatia and Erasmus MC, Rotterdam, Netherlands. Full and appropriate consents were obtained from all participants.

Methods

A sub sample of the total cohort, comprised of young people from the UK (West Midlands site), the Netherlands, Croatia and Ireland who at the 2-year follow-up completed time point four (T4) interviews and questionnaires were invited by their local Research Assistant (RA) to take part in a qualitative interview. Two hundred and seventy two young people completed T4 (UK = 85; Netherlands =123; Ireland =36 and Croatia = 28) and from this group, thirty four young people indicated their interest and gave their consent to the RA for the interview, a response rate of just under 13%.

Sub sample overview

The number of interviewees from the four partner countries was as follows: the UK (N= 9), Ireland (N= 10), Croatia (N= 10) and the Netherlands (N= 5); all were in the age range 17-24 years. They had been attendees of CAMHS (all services offering a range of psychiatric and multi-disciplinary interventions and support) until the service boundary when they had either continued in specialist mental health services (including staying at CAMHS) or been discharged. They had a wide range of mental health diagnoses and different living situations (e.g., living at home, independently or in care; working or in education). The cohort included 16 young people who had been referred to AMHS, of whom 11 had received some form of adult mental healthcare by the time of interview. This included 3 young people who had used private services and 3 who had already left AMHS, with 2 giving negative experiences as the reason for this.

Interview procedure

MILESTONE research assistants administered the interviews in the four countries over the period of one-year, either face-to-face or by telephone and in the young person's local language. A semi-structured format and note cards listing different topics allowed the young people to identify and select the issues of most interest or concern to them; the questions explored: (1) young people's experiences of preparing to leave CAMHS; (2) for those referred to AMHS or other services, their involvement in the decision-making about this referral and how this move went; (3) views of those discharged from CAMHS without referral or transition elsewhere; (4) what young people thought was important when moving from CAMHS. Words on the note cards included amongst others: autonomy, communication, confidentiality, consent, empowerment, involvement, waiting lists, medication, respect, self-determination and stigma

Data analysis

Interviews were transcribed verbatim by the research assistants undertaking the interviews or by a professional transcription service. Those from the UK and Ireland were in English; those from the Netherlands and Croatia, in Dutch and Croatian, were translated to English by professional translation organisations. Drawing on the six phase process set out by Braun and Clarke (2019), all transcripts were then read, reviewed, manually coded (initially and then combined) and thematically analysed, with themes defined independently by two MILESTONE

researchers (CS, ENic) with a third MILESTONE researcher assisting in refining them (FMcN). In analysing the data, and considering whether these revealed any new or contrasting issues or themes compared to previous research in the field of transitional care, the researchers kept in mind both the study of the ethical aspects of transition from CAMHS to AMHS (O'Hara *et al.*, 2020) and the systematic review of literature on the ethical aspects of transitional care (Paul *et al.*, 2018).

Throughout, the analysis was underpinned by a flexible coding process and the later development of themes through the clustering or collapsing of similar codes which had highly similar meanings, again in line with the principles for deriving themes set out by Braun and Cohen (2006). Themes identified through the analysis included: continuity of care; trust and respect in relationships with clinicians; the importance of the co-ordination of care; planning and managing change; moving services and moving to adult care; endings of care; autonomy; independence; choice; information sharing; involvement of parents and carers.

Results

Data gathered from the interviews revealed a complex picture of varied practice across mental health services working with young people. Similar to previous studies of young people's experiences of CAMHS and in particular, transition, positive experiences of young people enjoying trusted working relationships with their clinicians and feeling ready to move on, were noted. However, there were also a wide variety of examples of very limited involvement of young people in decision-making about their care after CAMHS. These were marked by discontinuities of care, a lack of robust processes for discharge or transition planning, often resulting in sudden departures from CAMHS accompanied by a wide-ranging lack of information.

Like many young people before them, these interviewees highlighted the importance of having a respectful relationship with their clinician, with their views heard and taken seriously. This was seen as the key starting point for young people feeling informed, engaged and involved in decisions about their mental healthcare, with their confidentiality protected, especially when discharge or transition was under consideration. Similarly, many highlighted the important role played by parents and carers in supporting them with their mental health.

Two sub themes, diagnosis and medication management, both closely linked to information sharing, choice and relationships with clinicians, were generated during data analysis. These are the focus of the following discussion since they have been less widely reported on in the transition literature. Both appear to be important influences on a key research question within MILESTONE, namely how and why some young people experience an optimal transition from CAMHS.

Mental health diagnoses, aid or impediment?

As noted earlier, analysis of the MILESTONE cohort profile (Gerritsen *et al.*, 2021) indicates that many of the young people had serious mental health problems. Information gathered from clinician or medical records indicate that the most common clinical classification was depressive disorders (26.6%), followed by anxiety disorders (22.5%), attention deficit hyperactivity disorders/ADHD (20.1%) and autistic spectrum disorders/ASD (14.9%). Over half (58%, N=443) had more than one clinical classification, 27.9% (N=213) had two classifications and 10.2% (N=78) had three or more classifications. Such data highlight both the complexity and range of mental health issues presented by young people at the upper age limits of CAMHS, the challenges of diagnosis and also, the likelihood that some might require prescribed medication post-CAMHS.

In the qualitative interviews, the importance of having a diagnosis was frequently raised, often in connection with young people trying to make sense of their symptoms or to understand what treatment CAMHS was offering them. One Croatian interviewee explained, *“I am going there (to CAMHS) for a reason, to get a diagnosis”* (C YP). For some, a diagnosis provided a way to explain their difficulties to others, of particular relevance at the point of leaving CAMHS when, several young people suggested, it would be especially helpful to having a letter explaining their diagnosis, working or formally classified.

In these instances, young people welcomed having a diagnosis, seeing it as an enabler and an aid to communication: *“I would be quite open to telling people because I feel like if you tell people it kind of helps (them to understand)”* (Ire YP). Furthermore, it could provide validation of their experiences: *“I think when you have a diagnosis it helps you realise actually there is something, I am being believed.... it is not just what I thought I had, I do have it... and yes, I think that is really important”* (UK YP). A diagnosis could also give young people confidence

since it reassured them to, *“know it was not just them going through it”* (UK YP) or it helped because, *“for so long I didn’t understand”* (Ire YP). Additionally, it was valuable in terms of self-management: it aided young people to *“know what to do in certain situations”* (UK YP), or to be *“more aware of it and learn how to deal with it better”* (Ire YP).

It was apparent, however, that not all young people had received or understood their diagnosis. Limited explanations were less than helpful: *“I didn’t have a full understanding of it because I wasn’t told anything... you know, it was just a diagnosis and that was it”* (UK YP). Others described wanting more of a sense of services/clinicians actively working with the young person around their diagnosis, rather than diagnosis being seen as an outcome in its own right. One young person elaborated, *“once they had told me what it was, they were kind of like... ‘OK this is what you have, now go away and fix yourself’ kind of thing”* (UK YP).

Not being given a diagnosis, or not having its implications explained, had left some young people feeling that no one knew what was wrong. This had adversely affected their confidence that they could recover: *“at least if you know something, OK this is what’s wrong, you can kind of work with it”* (Ire YP).

For some, the time taken to receive a diagnosis was problematic – one Dutch interviewee talked of how they would have, *“preferred sooner since then you are working with a goal”* (NL YP). In several cases, young people appeared to have encountered structural barriers in terms of which services could give young people a diagnosis – for example, one young person from the UK accessing a local crisis team reported being told the service could not diagnose young people if they were under the age of 18. Others recounted worries that they had to have a diagnosis in order to access treatment, including possibly medication, but questioned if their diagnosis was actually correct. Again, such worries became more marked as they approached transition and they were unclear if adult services would accept them.

Concerns about out-of-date diagnoses that left new problems at risk of being missed were another issue: *“I don’t actually think I’ve had any check-in as to whether my diagnoses are right since I was 18”* (more than 2 years ago, UK YP). However, young people were mindful of the need to be sensitive as to when and how to share diagnoses with young people which could justify a delay in some circumstances. For example, one interviewee from Croatia

suggested that perhaps this was not advisable immediately after an emergency admission when a young person might feel especially vulnerable.

Despite a wish expressed by many young people to receive a timely and adequately informed diagnosis, the picture is more complex and contradictory, for even when they did receive a diagnosis, there could still be difficulties. For example, some highlighted how unhelpful a very 'generalised' diagnosis could be; whilst this might provide some certainty, the problem was that it often failed to take any account of what one young person called, "*deeper issues*" (UK YP). Another explained that it, "*seems a bit too like everything has to sort of fit into one area.... Just saying you have depression, well that could have a really wide range of meanings, and the same with anxiety and stuff....*" (UK YP) Where there was a lack of certainty over diagnosis, one of the Irish interviewees described feeling that concerns they had raised, including symptoms, felt disregarded; they had been: "*mentioned almost in passing.... Or brushed under the rug*" (Ire YP).

Further complicating their wish for greater diagnostic clarity, were young people's fears about being labelled or defined solely by their diagnosis. For some interviewees, this emanated from experiences of being suddenly treated like a different person, or of feeling that they were being made to fit a certain diagnosis, possibly for reasons of convenience to the clinician: "*I think it's far too easy to treat someone as an illness and blame everything on that and not assess that maybe that illness is no longer an issue*" (UK YP). Another, who had found being given a diagnosis initially helpful warned, "*the doctors need to truly believe it, not use it as a convenient label... work with it but not exclusively on it ignoring other issues*" (Ire YP).

Furthermore, just as diagnoses were often abruptly given, sometimes seemingly issued more to fit with the demands facing the service (e.g. to provide routine diagnostic data), some young people reported experiences of diagnoses also being removed, without any explanation. In these circumstances, it seemed that the driver behind the decision reflected other pressures (e.g., to justify a decision to discharge a young person from the service), as illustrated by the following experience of one young person: "*they basically undiagnosed me with depression, so apparently I am no longer depressed*" (UK YP).

Medication management when moving service

In the main MILESTONE study cohort (Gerritsen *et al.*, 2021), at baseline, fifty-seven percent reported use of prescribed psychotropic medication in the previous six-month period. Nearly one third (29.4%, N= 224) had used two or three different psychotropic medications and a few (3.15%, N=24) had been prescribed four to five different psychotropic medications. Almost one in three of the cohort (28.3%, N=216) had been prescribed antidepressants; 14.4% (N=110) had been prescribed psychostimulants; 12.1% (N=92) had used antipsychotics; 5.5% (N=42) had used melatonin and 5.6% (N=43) had used benzodiazepines.

Medication had played an important role in the CAMHS experience of a number of the interviewees and some described how they had felt well informed and had received advice tailored to their needs. However, others were less positive and highlighted a need to improve information about how the drugs they might be prescribed worked, how long they might be needed, possible side effects, arrangements for monitoring and discontinuation plans. One young person requested more careful thinking about and information when young people were prescribed more than one medication: *"I think people need to work hard to get the right drugs, or the mix"* (UK YP). Another, also from the UK, called for, *"more balance in who has a say (about the decision to prescribe)"* and expressed the view that too much of the communication about medication had been directed at their parents. Such issues had particular salience when thinking about leaving CAMHS and taking on a more autonomous role in their mental health care.

Discharge back to their GP after leaving CAMHS was a quite common outcome for these young people, in particular, the Irish and UK interviewees. Many experienced this as almost a default position which lacked a robust care plan. Some felt this was indicative of their mental health not being valued, especially if their GP did not seem to have adequate mental health knowledge. With respect to medication management, whilst GPs usually took over the routine care of medication prescribing, a number of young people had encountered difficulties. For example, one Irish interviewee reported that their GP had refused to prescribe their medication despite CAMHS asking them to do this. Some concerns about clinician expertise were also voiced. At its most serious, this had led one young person to consider an abrupt discontinuation: *"I just stopped taking Prozac because I kind of thought, OK, like I'm not taking it when nobody is monitoring it, like I don't think the GP has sufficient knowledge to be giving people tablets that are so kind of mind altering you know?"* (Ire YP).

Positive experiences of how their medication had been managed at the point of transition included the following examples: one young person from the UK reported being given advice on how they could adjust their dose if they became anxious. Another, from Croatia, described their medication being tapered off close to their discharge from the service with their doctor promising ongoing medication involvement post-18 if needed. They explained, *“I made a deal with the doctor because I was taking medication that if I needed anything, I can call him and come (to CAMHS)”* (C YP) – although this offer, whilst viewed by this young person as welcome, raises questions regarding why such practice was necessary and suggests an absence of post-CAMHS arrangements.

Discussion

Discontinuity of care at the transition boundary between CAMHS and AMHS has been identified as a *“major socioeconomic and societal challenge for the EU”* (Signorini *et al.*, 2018). Their findings revealed, amongst other things, that in many countries there are: a paucity of procedures and processes for handing on clinical information about a young person’s ongoing mental health needs; very limited evidence of joint working or partnership working involving the young person in planning their transition and facilitating continuity of care, and that in most of the 28 countries surveyed, it appeared there was no system in place to ensure accountability from a single clinician from either service to co-ordinate a young person’s transition. It is within this context that the young people’s experiences documented in this paper should be viewed.

The issues young people raised about diagnoses and medication management have obvious relevance to both continuity of care and also, the matter of them becoming autonomous agents in their care at the point of moving on from CAMHS. O’Connor and colleagues explain that diagnosis is an important step in the everyday practice of mental health care; it informs and shapes clinical decisions regarding which treatment pathways are chosen (O’Connor *et al.*, 2018). Furthermore, they note that at a practical level, a diagnosis can facilitate access, or alternatively, can exclude young people from resources, treatment and prognosis. They conclude that appropriate diagnostic labels positively affect help-seeking and through the ‘common language’ that diagnoses can provide, may benefit service-users

by streamlining communication between different services and clinicians involved in their care.

Historically, there has been caution in CAMHS about giving young people an early and definitive diagnosis. This is due to concerns regarding the transient nature of some symptoms, changes that result from a young person's developmental stage (O'Connor *et al.*, 2020), the readiness of young people to receive it and avoiding secondary adverse effects from stigmatization (Mental Health Foundation, 2021; Corrigan, 2007). Findings from other research conclude that diagnostic classification can affect a person's self-concept and social identity in both positive and negative ways. For example, it may provoke grief and despair, especially if the diagnosis is associated with poor prognosis and treatment options, or worries about 'self-fulfilling prophecies' (O'Connor *et al.*, 2018), the latter having strong associations with the labelling theories that were prominent in the 1960s, notably in the work of Scheff *Being Mentally Ill*, originally published in 1966 (Scheff, 2017). In the interviews described in this paper, the contradictory and conflicting emotions that may be provoked through receipt of a diagnosis were evident: some of the young people, whilst wanting to receive such information, also expressed fears about being labelled or being made to 'fit' or defined solely by a diagnosis, with any other concerns they might have being ignored or not taken seriously.

However, overall it seemed that most of the young people interviewed were clear about the benefits of receiving an early and accurate diagnosis and of this being subject to regular review. This accords with a variety of studies that have described provision of a mental health diagnosis as providing hope and empowerment (Farooq *et al.*, 2018; Milton *et al.*, 2015), indeed some have described it as pivotal for those using services (Perkins *et al.*, 2018). A diagnosis helped them understand the treatment they were receiving and for some, it provided important validation that their problems were real, that their symptoms came from a genuine and independent disease entity and they were believed (Horn *et al.*, 2007, cited by O'Connor, 2018). The value of diagnosis in tackling the sense of isolation and of being the 'only one' described by some of the interviewees, is echoed in work by McNamara and Parsons who explain that diagnosis can support contact with similar others, providing an avenue for social support (McNamara and Parsons, 2016) and a sense of belonging and validation (Jones, 2015).

Where young people appeared not have been given, or were unaware of any diagnosis, this was also described as unhelpful, not least since some described feeling that this meant that no one knew what was wrong which had adversely affected their confidence that they could recover. Such a lack of diagnostic information has been identified in other research as a major cause of disempowerment (Pitt *et al.*, 2009). Furthermore, it falls far short of what O'Connor and colleagues call for to ensure that diagnoses are communicated and managed in ways that optimise mental health outcomes, namely: “*understanding young people’s first-hand experiences of receiving and living with a diagnosis is paramount*” (O'Connor *et al.*, 2018).

A further complication in giving young people a mental health diagnosis, is the growing interest in transdiagnostic approaches, resulting from the identification of similarities across diagnoses, this leading to a shift away from single-diagnosis protocols (Gutner *et al.*, 2016; McGorry and Nelson, 2016). Whilst this may be understandable from the perspective of clinicians, bearing in mind the concerns raised by the interviewees about generic or ‘catch all’ diagnoses that failed to take account of their individual circumstances, it may be less than helpful for young people seeking something more specific, be this for validation or self-management purposes.

The fundamental requirements for good information sharing of clinical and diagnostic information across services (Street *et al.*, 2018; NICE, 2016), have been widely reported on and includes information about prescribed medication. This is highly pertinent given that over the last decade, significant increases in psychotropic medication use by young people, for example, antidepressants, have been noted (McMillan *et al.*, 2022). Medication is often an essential part of mental health treatment, including the treatment or reduction of symptoms and preventing relapse or escalation of a disorder.

However, in recent years, as pressure on mental health services has grown, resulting in longer waiting times for psychological therapies, concerns have been noted about the increased use of medication in young people, in lieu of these other mental health treatments (NIHR, 2020). Whilst the benefits to a person’s care quality and overall health of being actively involved in decisions about medication have been increasingly recognised (Delman *et al.*, 2015), studies have also highlighted the harmful impact on people’s sense of

autonomy resulting from limited involvement in decision-making (McMillan *et al.*, 2022). Affecting service users of all ages, a lack of choice about their medication and a poor prescribing experience, have been noted, with prescribing psychiatrists described as not sufficiently acknowledging the negative impacts of medication on life quality and physical health concerns and patients left feeling powerless to influence decisions about their medication (Morant *et al.*, 2017).

Among the young people interviewed, arrangements for future prescribing, and monitoring of medication were in the forefront of a number of their concerns as they were discharged or moved services. Many noted uncertainty as to what was planned or wondered who would be responsible for monitoring once they moved on from CAMHS. Whilst there were a few examples of shared decision-making between clinicians in CAMHS and young people, and contingency planning (for example, the information given to one of the interviewees about how to adjust their medication if they became highly anxious), a common theme was that much more communication and explanation is needed – and as one young person highlighted, more careful thinking about the prescribing of combinations of two or more different medications, something experienced by nearly a third of the total MILESTONE cohort. Furthermore, the role of GPs, and their competency to manage such prescribed medication regimes was questioned by some of those interviewed.

Considerable time pressures on CAMHS arising from significantly increased demand for specialist mental health services have been evident for some while (UNICEF, 2021; Children’s Commissioner, 2021). These are compounded by workforce pressures including high rates of staff turnover (BMA, 2019; CQC, 2017). It is hardly surprising that this environment is adversely impacting on the time clinicians can offer young people in planning for discharge and/or transition from CAMHS, including how, when and what diagnostic information is shared and with whom, and the planning of ongoing management of prescribed medication. This is to the detriment of young people’s confidence to become more autonomous for their healthcare as they depart CAMHS. Similarly, pressures and workforce shortages in both AMHS and GP/primary care, are likely to adversely impact on the time they can offer in ‘receiving’ young people and the time young people may have to wait before they can access services. Such circumstances make it even more vital for young

people to have sufficient information and understanding about their mental health diagnosis and any medication they may require before leaving CAMHS.

Implications for practice

Despite over a decade of national health guidance and policy emphasising the need to improve the information sharing, decision-making processes and continuity of care relating to young people accessing mental health services, and in particular, those in transition between services, the data presented in this paper suggest that everyday practice in mental health services often continues to fall short. This includes the management of diagnoses and prescribed medication for young people at the upper age CAMHS boundary. A lack of or unclear diagnosis and/or a non-existing medication plan, contribute to unsatisfactory discharge or transition experiences which can have a knock-on effect in other areas of young people's lives.

Improving the way practitioners in mental health services provide diagnoses to young people includes raising awareness of the need for them to be sensitive to the possibly ambivalent feelings and fears young people may have about receiving such information. Here they need to draw on the learning from existing research about young people's direct experiences of psychiatric diagnosis and its impact on their self-concept and social identity, also its potential influence on young people's relationships with clinicians and their contact with mental health services. Other considerations include: how to ensure timeliness in the sharing of diagnostic information and also, who it should be shared with, and how to keep diagnostic information under regular review and up-to-date.

With regard to medication management, a number of implications for prescribing practice are evident. These include ensuring the adequacy of information provided to young people about how long they might need to take any prescribed medication and possible side effects, including when a medication is discontinued or a combination of drugs are required. Effective processes for monitoring and contingency planning for any difficulties young people might encounter as a result of taking medication, also need to be in place. NICE has highlighted that between 30-50% of medications for long-term conditions are not taken as intended (NICE, 2015), which evidences the need for good engagement with those individuals being prescribed, and effective monitoring arrangements.

With regard to medication management post-CAMHS, important questions about GP practice are posed. Not only are GPs a key gateway in to health services, they are increasingly involved with young people post-CAMHS (Appleton *et al.*, 2019). The study findings indicate work is needed to address firstly, young people's perceptions of how GPs can support them and secondly, to ensure that GPs' are equipped with the requisite prescribing knowledge, skills and information to support those leaving CAMHS and referred to their care.

Strengths and limitations

The strengths of this study are firstly that it involved young people from the first large pan-European research study with a focus on transition between CAMHS and AMHS. Secondly, the young people interviewed had a wide range of experiences regarding mental health services from four different countries and thirdly, the data gathered revealed a variety of complicated issues that can impact on transitional care, some more novel in the CAMHS and transition research field. Despite some inter-country variations in how CAMHS and AMHS are delivered, the key themes were similar suggesting that some fundamental policy, practice and service structure problems exist that go beyond any particular country's cultural attitudes towards mental health care for young people.

The limitations of the study include that only some of the interviewees had experience of transition from CAMHS, that only a small number had actually been seen in AMHS and that the number of interviewees from the Netherlands was quite small.

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Appendix 1: Milestone Consortium members and partner institutions

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