




A cross-cultural qualitative study of the ethical aspects in the transition from child mental health services to adult mental health services

Lesley O'Hara¹ , Ingrid Holme¹, Priya Tah², Tomislav Franic³,
Nikolina Vrljičak Davidović⁴ , Moli Paul^{2,5} , Swaran Preet Singh², Cathy Street²,
Helena Tuomainen², Ulrike Schulze⁶, Fiona McNicholas¹ & The MILESTONE
Consortium[†]

¹School of Medicine, University College Dublin, Dublin, Ireland

²Mental Health and Wellbeing Unit, Warwick Medical School, University of Warwick, Coventry, UK

³Department of Psychiatry, University Hospital Split, Split, Croatia

⁴Department of Psychiatry, Clinical Hospital Center Split, Split, Croatia

⁵Stratford Healthcare CAMHS, Coventry and Warwickshire Partnership NHS Trust, Stratford-upon-Avon, UK

⁶Department of Child and Adolescent Psychiatry/Psychotherapy, University of Ulm, Ulm, Germany

Background: Transitioning from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) raises novel ethical aspects for healthcare professionals, as well as for young people, their parents and carers. **Method:** Focus groups were conducted in Croatia, Ireland and the United Kingdom with youth mental health groups and youth representatives with no mental health (MH) remit. One hundred and eleven participants, aged from 16 to 60 years, contributed to discussions. **Results:** Perpetuation of stigma, autonomy and decision-making were central themes as both enablers and deterrents of successful transition. The tension between professional (and at times parental) paternalism and young persons' growing autonomy was well captured in the themes; (a) desired practice, (b) who should decide, (c) the process of decision-making and (d) potential harm(s). **Conclusions:** This study provides insight into the ethical values, particularly autonomy and collaboratively working, which people expect to underpin the transition between CAMHS and AMHS.

Key Practitioner Message

- Engaging young people early in making decisions about their future care can enhance trust between practitioner and the young person.
- In addition to diagnosis, a number of factors (such as moving home; waiting lists and stigma) may need to be taken into account when considering the direction of future health care.
- When possible, alternatives to AMHS should be considered if considered by the young person to be a less-stigmatising treatment option.

Keywords: Transition; child and adolescent mental health services; adult mental health services; decision-making; qualitative research; ethics

Introduction

Mental health difficulties are common in childhood, with estimates of one in five children having mild psychological distress, and one in 10 requiring specialist interventions (Ford, Goodman, & Meltzer, 2003). Many difficulties continue into adult years and require ongoing mental health (MH) care (Merikanagas et al., 2010). As upper age limits apply to most Child and Adolescent Mental Health Services (CAMHS), ongoing care requires a change in care provider. Whether these ongoing needs are best met in specialised tertiary Adult Mental Health

Care Services (AMHS) or other primary/secondary care level community-based services is unclear. There is an implicit assumption in healthcare policy and academic literature, and among services, that continuity from one specialist MH service to another might be optimum, providing continuity and facilitating engagement, but the reality is very different. Numerous studies report that this transition is poorly executed and experienced by many young people and their families and likely to hinder engagement (McGorry et al., 2018; McNamara et al., 2013; McNicholas et al., 2015; Singh et al., 2010). In situations where evidence is unclear as to what is beneficial, harmful or what represents best use of limited resources during care transition, research and service

[†]The members and partner institutions of MILESTONE Consortium group are listed in Appendix 1.

evaluation becomes a pressing ethical consideration (Khadr & Kelner, 2008).

Adolescence presents as a risk period for the onset of many MH disorders, and ensuring appropriate care and management at this crucial period where the young person (YP) is experiencing many other transitions seems prudent. Exploring and supporting YP's informed decision-making at the time of transition is essential, to ensure that those who need continued MH care receive it in an appropriate service context. Those who do not need a referral to AMHS may still need to be supported in another service and supported in accessing AMHS at a further stage. Understanding factors which contribute to the reluctance of CAMHS clinicians to refer on to adult services, even when there is a perceived clinical need, or YP opting out or refusing referral when offered, also need to be examined (McNicholas et al., 2015).

Bridging and optimising transition between CAMHS and AMHS is essential, but before using scant resources towards this endeavour, the underlying ethical context must be considered, and a range of perspectives used to shape the service. The ethical principles of nonmaleficence, beneficence and individualistic autonomy predominate medical practice, and these are also assumed to be ideal components of the transition from CAMHS to AMHS. However, the perspectives of YP, parents and carers must be included as potential users of the services. In addition, the transitional service must align with the ethical values of the wider cultural context where under 18s are increasingly engaged in healthcare decisions. There is long-standing evidence that, in general, 14- to 15-year-olds' capacity does not differ from adults' (Casimir & Billick, 1994; Weithorn & Campbell, 1982), and that YP want information about MH services to be provided to them whether they are referred or not, and they do not expect to be coerced (Paul, Berriman, & Evans, 2008). An EU funded project on transitions from CAMHS to AMHS MILESTONE offered an opportunity via secondary data analysis to examine the ethical values which people expect to underpin the transition between CAMHS and AMHS in Croatia, Ireland and the United Kingdom.

Methods

Focus groups (FGs) (12) were held to assist in the development of a psychosocial ethics questionnaire (Singh et al., 2010), for the MILESTONE study. MILESTONE researchers in Ireland, UK and Croatia approached local and national youth MH advocacy groups, as well as a number of nonmental health local groups and national agencies working with young people. Those interested in participating in the study were provided with a detailed information pack and invited to attend the focus group.

A facilitator guide detailing how the focus groups would be run ensured consistency across three countries. The researcher in the participating country assumed the role of moderator of the FG and was assisted by a research assistant who was responsible for note-taking and logistical tasks such as audio-recording and providing refreshments. At the outset of the FG, the purpose of the research, issues around confidentiality and anonymity, and the potential uses of the data were highlighted to all participants before informed consent was obtained. The researcher used a number of vignettes to introduce the topic and generate discussion (see Table 1). Vignettes are a well-accepted approach in qualitative research; seen as acceptable by participants, they are recognised as a valuable tool for eliciting participant insights on health service experiences (Lapatin

et al, 2012). In this study, each vignette depicted a fictional case in which a YP (with a particular diagnosis) was approaching the end of their care at CAMHS where a decision was needed regarding any onward MH treatment. Participants were asked to consider the cases and discuss any ethical issues raised. Prompts were used to encourage reflection.

In keeping with the theoretical sampling strategy of grounded theory (GT), data were examined after each FG and developing insights were explored in subsequent FGs (Charmaz, 2006). After 12 FGs, no new insights emerged and data saturation was considered to have been reached (Charmaz, 2006).

Following completion of the focus group, audio files were transcribed verbatim. Researchers at each site removed any potentially identifiable information and shared the pseudonymised data with the first author for the purpose of analysis.

Ethical considerations

Institutional ethical approval was obtained for all sites. Full and appropriate consents were obtained from all participants, including parental consent where required. Standard qualitative research best practice included using recruitment packs and safeguarding confidentiality (Bryman, 2016).

Secondary analysis

Analysis of the data was conducted over five stages. First, facilitators MILESTONE coded transcripts for the groups they were responsible for. Second, the first author (who acted as the coordinator for the secondary analysis) coded all transcripts by drawing on the coding principles of GT (Glaser & Strauss, 1967), including line-by-line coding and constant comparison. Third, MILESTONE acted as an additional coder for 10% of the transcripts. Fourth, regular data analysis meetings were held via telephone, during which the first author presented the analytic codes (produced through stages 1 and 2, and checked for trustworthiness through stage 3), and collaborated with the research team to group similar codes together and revise code labels. Finally, the first and second authors drafted the final analytic categories and the research team compared the categories with the data to test if they fit with the evidence. Revisions were made to the categories as agreed by the team. This process of comparison and revision was completed when the research team agreed on the final analytic categories. This iterative process allows for an analysis that is firmly grounded in the participants' accounts and the researchers' interpretation of these accounts.

While country comparison was not an aim of the original study (psychosocial ethics questionnaire), we paid attention to

Table 1. Examples of focus group vignettes

Condition	Case	Ethical tension
Depression	John is 17 years old and presented with examination stress and has been in CAMHS for 6 months receiving Cognitive Behavioural Therapy	John wants to end treatment while his key worker wants him to be referred as he has only been at CAMHS for a short time
Anorexia Nervosa	Claire is almost 18, attending CAMHS receiving family therapy	Claire is going to university and does not want onward referral, although her parents and CAMHS clinicians do
Obsessive Compulsive Disorder (OCD)	Kelly has been receiving CBT but continues to have OCD symptoms	Both Kelly and CAMHS agree on referral, and AMHS will accept her as a patient, but it will be a 9-month wait

differences in responses according to country due to the lack of comparative research in this area. Mental illness knows no boundaries, yet views and attitudes linked to mental health problems and help-seeking are shaped by cultural and historical forces, which can result in differences by country (Pescosolido et al., 2008).

Results

The final sample included 111 people aged 16–60 years of age (female $N = 94$, male $N = 17$). The majority of participants had experience of MH illness (31% with personal experience, 50% with a close family or friend).

Discussing the ethical aspects and challenges was a complex exercise in all FGs; however, the vignettes prompted rich discussion regarding the values which YP expect to underpin MH services, including the transition between CAMHS and AMHS. Ethical issues that emerged partly reflected topics discussed and were organised under the following headings; (a) desired practice, (b) who should decide, (c) the process of decision-making and (d) potential harm(s). Selected illustrative quotations are presented in the following text. The abbreviations CFG, UKFG and IREFG refer to focus groups conducted in Croatia, UK and Ireland and associated numbered separately. While we did not aim to explore country differences in depth, quotations are separated by country to reflect the variation presented between the FG in the three countries. This helps to highlight how the ethical issues for YP may differ based the MH services/practice delivered in those countries. Direct quotes are in italics.

Desired practice

Decisions regarding transitioning a YP from CAMHS to AMHS are complex, as suggested by a lack of uniformity in YP's views as to the best MH care pathway/outcome. Some groups suggested alternatives to the CAMHS-AMHS scenario, with new bridging service.

(...) there could be someone that like in the interim, the person can go to, so it doesn't feel like that such a long gap between the two services. (UKFG4)

We found evidence to suggest that the type of MH condition influenced the ease of decision-making in relation transition to adult services. For example, participants were more comfortable deciding in the best interest of Claire (anorexia nervosa) than John (depression). In relation to all cases, participants emphasised the person's right to autonomy, the importance of the individual wanting to take up the service, and the risk of harm if treatment options are forced on them; however, this was dependant on the MH condition of that person.

If a young person doesn't feel that it is her own decision, something that she wants, that would result only with opposite effect. And in any future situation, she will give up easily. Because she was forced to do it. (CFG1)

All groups included respondents who advocated actively working with the YP so that they understood and even agreed with the professional/parental view, while acknowledging that for some YP with certain MH conditions, this would not be possible.

Yeah, they should have some control. It depends on the mental illness (...) because some mental illnesses they can

convince themselves they're well and they're completely not. (UKFG2)

Regarding the desired practice all groups expressed a strong and clear regard for equality and that all YP should have equal access to MH services. Those in England seemed less concerned with stigma as a deterrent to transition and placed more importance on working with the YP and ensuring any further treatment plans were made based on joint decisions. Croatian participants were more definitive in actions required and accepted or proposed paternalistic views when required. Differences between the perspectives of participants in each of the three countries became apparent as FGs were conducted and highlighted the value placed on certain processes depending on where participants were based and the MH services available in those countries.

Who should decide?

The decision of whether a YP transitions to an adult MH service is ultimately up to the MH service that the YP is under the care of, in addition to the YP and parent (if appropriate). Unsurprisingly then, the question of who should decide about the need for subsequent treatment for a YP elicited varied responses. Many respondents believed this followed in parallel with the age of majority, in that autonomous decision-making typically accompanies adulthood, 'you know you are an adult, this is your time to make your own choices' (UKFG2) and this extends to decisions regarding MH care, for example 'She is an adult now...and she has a right to decide about her health conditions' (CFG1) moreover, 'she is going to be 18, in her eyes she's more independent' (IREFG1). However, specifically in the presence of mental illness, others perceived clinical expertise trumped personal 'it doesn't have to be her decision' (CFG 1), although acknowledging the associated risks.

So I don't think she's really had a choice in it, and if you don't have a choice in counselling you're not going to cooperate. (UKFG2)

FG participants cautioned that YP may refuse to engage with services if they feel that they have not been involved in, or listened to, during the decision-making process.

he will develop a feeling of mistrust towards environment and towards those who are trying to motivate him, exactly because they make him feel like he needs help. They don't trust him. (CFG1)

They also cautioned against decisions being based on diagnostic groupings alone; instead, each individual's unique experience of their symptoms needs to be heard and valued.

ethically how do you decide how big a deal a mental health issue is to somebody? Because everybody is going to experience that differently. So ethically I think that's a challenge anyway because my cutting my wrists or your eating disorder or your OCD or your agoraphobia is like massive to us because it's ours (...). (UKFG4)

FG participants considered the impact of a number of related factors facing YP, parents and clinicians in reaching a decision about the merits of future MH care. These included the likelihood of long-term engagement

with services, the chances for subsequent successful MH intervention and the level of collaboration between the YP and the clinical team. The groups were aware of the difficulty faced by the clinician or parent;

how scary that is for his parents and his carers and his friends to just be like “ok this is your decision, you go”. You know it’s very difficult to not try push. (IREFG2)

While at the same time alert to the risk of excessive pressure from clinicians, or family, which, even if stemming from their concern, may lead to negative outcomes, disengagement, or short-term gains, as there was a sense of being ‘forced to do it’ (CFG1). This contrasted with ‘empowering’ the young person,

(...) it’s like power dynamics, if you’re telling someone that they need to go somewhere and they might just feel obliged to do it because you’re telling them. Whereas she’s taking control of the situation, and I think they should respect that. (UKFG2)

Respondents prioritised a need to work collaboratively with the YP, encouraging rather than dictating attendance at AMHS, if deemed appropriate, and encouraging young people to ‘make the decision (himself) in order for it to have the best chance of working...’ (IREFG2).

The process of decision-making

A negotiated decision-making approach was presented as a way of establishing a level of autonomy for the YP, while also acknowledging clinical expertise and experience. Participants, particularly in Ireland and England, where approaches to MH care are similar, discussed ways in which this could be achieved, by truly informing the YP, providing adequate and comprehensive information, delivered in a timely and planned fashion, and in an accessible way that is understandable to the young adult.

So it’s like realistically this should have been thought about a while ago and there should have been a consistent process leading up. (UKFG2)

Such decision-making should include information about AMHS but also other alternative services in the community. For example, one Irish young group member cautioned against ‘being so single minded towards the referral to adult’ (IREFG2) and another alerted us to the adverse effect of pushing the YP as this would ‘get a cut off from her’ where she would ‘shut down and say no’ (IREFG2). Both group members advocated for alternative community and personal supports to be included in decision-making options.

Like she needs that 6 months of all the information she can get on what adult [service] can do for her. And also what student health can do for her. And how she can manage herself as well. (IREFG1)

Providing the YP with all the relevant information necessary to decide for their future care, not only enables them to make an informed decision, but also has the potential to bolster their own sense of independence, autonomy and control. This was perceived best if planned and delivered ahead of time.

There was acknowledgement of the changing role of the parents/family/carer as the YP moves from being a child to an adult and difficulties they had in ‘letting go’

(IREFG1). The groups discussed the importance of providing adequate information to the family of the young adult, who up to this point may have been involved in, and responsible for, decisions regarding their care, to allow them confidently say ‘OK, this is your decision, you go’ (IRE FG2). Participants were also alert to possible conflicts of interest, between clinicians’ duty to respect patient (young adult) confidentiality, and a wish, if not a right, of a parent or carers, to know what is going on, and to be alert to any risk. This might differ based on the differing legal landscape across the three countries. This also extended to an awareness of a YP’s need for ongoing care. It was suggested that parents or carers might need support in this move to a more peripheral position and integral to ensuring a smooth transition for the YP:

The parents will need an awful lot of support [...] there has to be this trust between everyone that they can try and work closely with Claire alright and kind of visit her or she comes home at weekends or whatever. But I think the parents will find it very difficult kind of letting go of that. (IREFG1)

Respondents recognised that the legal age of 18 brings expectations of autonomy and decision-making powers, but they were also alert to the variations and limitations of adopting a solely age-based approach to capacity with age alone being a poor predictor of maturity:

You see some people and at the age of 15 they’d be more mature than someone that you know at the age of 30 something. [...] And how do you measure maturity? (IREFG2)

The discussions emphasised the importance of careful consideration in the decision-making process. First, there is a need to balance expectations of autonomy and self-governance in the young adult with a consideration of competency. Second, there is a need to value prior and possible ongoing requirement of support from parents. There needs to be a collaborative approach to the provision of adult MH care, affording a place for the family, while also promoting autonomy, dependent on age.

Potential harm

Stigma, as a potential harm, was mentioned in all FGs as a reason for not referring on to AMHS or for preferring community counselling services rather than AMHS. Concerns were raised regarding the labelling of mental illness, more evident in potential AMHS referrals and the implications of this for a YP’s journey into adulthood. However, we found some differences between countries. Stigma was a strong theme in both the Irish and Croatia FGs which likened mental illness to a burden being carried ‘on his shoulders’ (IREFG1) and using terms such as ‘asylums’ to describe AMHS treatment (IREFG1). When stigma was referred to in the English FGs, it was not expressed as strongly.

I was gonna say it can be quite stigmatising. I guess because there is family involvement in the CAMHS services and maybe not so much in the AMHS cos there isn’t the money for it. (UKFG3)

While more research is required to assess how far these differences reflect public awareness campaigns of mental health, two forms of stigma were referenced; treatment-stigma and self-stigma, the quantity and quality of which differed between CAMHS and AMHS.

Stigma from CAMHS treatment was generally seen as transient and removable, a 'more temporary' and 'a short-term thing' (IREFG2) and from the UK group as stigma 'sort of on you then isn't it' (UKFG3). However, the label of being 'mentally unwell' was presented as something that accompanied the YP for the duration of their attendance at MH services. As such, this label remained if travelling from CAMHS to AMHS. Attendance at MH services, therefore, is the factor which ascribed a label of being 'mentally ill' to the YP. This label was seen to have the potential to mark the YP as different to their peers. For example, when one focus group facilitator probed the reason a person may not wish to transition to AMHS,

they mostly leave for college in that age, they meet new friends. That can probably cause them problems. They are marked. (CFG1)

By comparison, the quality of stigma derived as a result of treatment in AMHS was seen as different because the MH conditions treated by AMHS were 'more severe' (IREFG2), and respondents drew on their own cultural and social perspectives of AMHS. For example, Irish groups referenced 'the big asylum' to explain why using adult services carries a stigma that 'stick[s] with you for the rest of your life...'. (IREFG2). Thus, our participants experienced that a YP referred to adult MH services, retained their label longer, along with a sense of a more serious and enduring illness.

Self-stigma was also identified as a possible deterrent to transitioning to AMHS since for some young people, this was seen as confirming they had a severe illness, which in turn, would disadvantage them in other areas of their lives such as getting a job. Attending a new service and the need to repeat their history, to new and changing clinicians, 'retelling everything all over again (CFG1)' might also lead to perpetuation of stigma. Transition to nonAMHS type services, such as primary care counselling, was not associated with the same degree of stigma.

Discussion

This paper examined the ethical aspects and values which YP and their social network consider as important when considering the case of a YP who potentially may transition from CAMHS to AMHS. Consideration was given to the pathway of care from CAMHS to AMHS, to the deficits in the transition process, and to the potential harms which may be caused by transition. Clinical vignettes were constructed by the research team and were used to facilitate discussions with individuals from youth MH groups and from youth advocacy groups with no mental health remit.

Our findings reveal a range of ethical issues relating to the desired process of transition, who should decide, the process of making decisions about transition and potential harm that may result. These indicate that several key ethical challenges need to be addressed.

Challenge 1: Improving the decision-making process

To achieve a desired outcome, participants were in agreement that all YP should have access to suitable MH

services when needed and that transition between CAMHS and AMHS should occur in the context of certain MH conditions but should not be forced upon the individual. With regard to who should decide and how, an informed and flexible approach which is respectful of the autonomy of YP but also safeguards their mental well-being was advocated for, but this poses a number of practical challenges.

In Ireland, Croatia and the UK, the decision and preparation for transition from CAMHS to AMHS occurs prior to the person turning 18 and therefore takes place while the person is a child. Children and YP's rights to participate in decision-making about their health care are widely acknowledged and underpinned by the United Nations Convention on the Rights of the Child, although it does not imply they should always be the main decision-maker (United Nations General Assembly, 1989). The legal landscape regarding consent to treatment, which varies from country to country, is likely to influence clinicians' decisions about who has the final say, and the experience of the youth attending services. Research suggests that having the final say may depend on who is legally able to provide a valid consent or refusal to consent (Paul, 2004).

At the transition boundary, YP are in the middle of several broader transitions into adulthood; those with serious MH conditions may have delayed psychosocial development and be struggling to enter into valued adult roles (Davis, Geller, & Hunt, 2006). While YP who have reached the age of legal majority may have greater legal and political rights to self-determination, working with patients who are capable of being ethically, cognitively or socially autonomous but are still dependent on their parents in legal, social or relational terms poses complex ethical dilemmas. This is especially the case when there is concern that the YP is making a decision that may result in some sort of harm (Paul et al., 2008).

The FGs point to the need for the YP to be able to take on individual responsibility for their choice in future care pathways. This is an evolving process, one less determined by age but by maturity and taking into account any disabling competency issue linked with their mental illness. FG respondents argued with each other about the role the clinician played in shaping the YP's decision and recognised the uncomfortable position that parents hitherto carers found themselves in as they struggled to support their child's growing autonomy, but were nervous about possible ill-judged decisions. Parents of children with MH problems may feel less satisfied and reassured and experience greater discomfort and pessimism when faced with the onset of adult autonomy in their children. This natural shift in autonomy from parent to (adult) child needs to be carefully managed, individually timed and services need to be flexible in their ability to incorporate ongoing parental involvement, even in the presence of age of majority.

How might a transitional service address this concern? From a practical perspective, one specifically aired by members of the FGs is that a jointly negotiated transition should be implemented. As a YP is approaching CAMHS transition boundary, discussions about future need and future family roles should be held early and often, with a gradual shift in degree of responsibility from the parent to the YP, contingent with their capacity and

facilitating the development of confidence and competence in the process. This process should not only include information on AMHS, but also alternatives and the clinicians should gently probe whether there are any spoken or unspoken concerns the YP or their family have that might limit transition options. This might allow an examination of the need for ongoing parental involvement, despite the young person reaching age 18, and entering adult services. This suggests that an effective transition service between CAMHS and AMHS may require development of national policy frameworks regarding YP's legal healthcare rights.

Challenge 2: Negotiating potential harm(s)

Discussions pointed to the transition from CAMHS to AMHS as serving to perpetuate MH stigma and therefore act as a barrier to attendance at MH services. On the other hand, counselling and general, as opposed to specialist, MH support provided in community services seem an acceptable alternative to participants in Ireland and England, with the potential to alleviate the stigma associated with service attendance. The experience of self-stigma related to mental illness has been recognised by other groups (Corrigan & Watson, 2002) and has been linked to embarrassment and shame. Stigma has been recognised as a major barrier to effective help-seeking (Wrigley et al., 2005), and this includes stigma by other and self-stigma, evident in the responses by members of the FG. How or whether attendance at intermediary nonspecialist MH services (e.g. counselling) contributes to the reduction of self-stigma, and improved engagement and outcomes, despite different expertise, need to be examined more carefully. Although research suggests that widespread stigmatisation of YP with MH difficulties starts from childhood, YP, when compared with adults, were more accepting of their peers with MH difficulties (Kaushik, Kostaki, & Kyriakopoulos, 2016). This suggests that discussions regarding stigma should occur early on in CAMHS (YMCA, 2016). As personal stigma has been found to be significantly and negatively associated with measures of help-seeking, the identification and management of self-stigma amongst attendees is crucial to exclude this as a barrier to successful transition (Eisenberg et al., 2009). In fact, research has also shown that some YP want continued engagement with AMHS, when part of their identity is related to their MH illness (McNamara et al., 2017).

To address these challenges, the longitudinal arm of MILESTONE (Tuomainen et al., 2018) will provide an opportunity for the examination of the effects of stigma and other barriers to transition in a large sample of CAMHS attendees ($N = 763$) followed up for a total of 24 months. Clinical outcomes will be examined based on different transition pathways, from those who continue to AMHS, those who disengage or are discharged, or those for whom planned alternative services are offered. Via a study-specific questionnaire, YP will offer their views on their role in transition planning, their experiences of any ethical dilemmas associated with transition and the presence of any stigmatising attitudes. A qualitative methodology will allow any themes identified to be further explored through focus groups.

This will add to the themes already established in this paper.

Strengths and limitations

These FGs were conducted in three countries with a varied group of YP or advocates of YP with MH difficulties. Despite some differences between the countries – for example, with regard to the impact of stigma about mental health and views towards when clinical expertise might need to take precedence over a young person's autonomy, the key themes identified were similar across countries suggesting fundamental issues and concepts about transition, rather than country-specific service provision and related attitudes. The salience of these issues highlights the need to attend to the ethical issues associated with transition from CAMHS to AMHS across Europe, and this is something which will be addressed by MILESTONE.

In keeping with the GT approach of the research, this paper is limited by the extent to which it portrays the perspectives of our research participants, rather we offer an account which has been constructed through the researchers' analysis of the data, and in the case of the Croatian data, findings have been generated through the researchers' analysis of the participants' translated accounts.

Questions and comments made by some respondents, who had not accessed or understood MH services, were hypothetical and prompted by vignettes. Future research must examine the views and experiences of youth who have made a range of transitions, both to speciality and community services.

Before we invest what scarce resources remain in the current restricted economic climate, proper evaluation of service developments becomes a priority. MILESTONE, by examining transitional care pathways have shed some light on this. Balancing outcomes based on researcher and clinical prerogative with what is perceived as crucial by the YP also needs to be carefully considered. As with all services, the service user must be central to the research and involved in the evaluation process. Such services need to be sustainable and meet the full range of needs of the individual.

Acknowledgements

The research leading to these results has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442. This paper reflects only the authors' views, and the European Union is not liable for any use that may be made of the information contained therein. The authors have declared that they have no competing or potential conflicts of interest.

Ethical information

The study received ethical approval from Saint John of God Research Ethics Committee Research Proposal (Date: 18th July 2014, Application number: No. 583), University of Warwick, UK and Klinički bolnički centar Split, Croatia. Full and appropriate consents were obtained from all participants, including parental consent where required.

Correspondence

Lesley O'Hara, Saint John of God Research Foundation clg, Saint John of God Hospitaller Services, Stillorgan Rd, Stillorgan, Dublin, A94 X5K8, Ireland; Email: lesley.ohara@sjog.ie

References

- Bryman, A. (2016). *Social research methods*. Oxford, UK: Oxford University Press.
- Casimir, K.C., & Billick, S.B. (1994). Competency in adolescents' inpatients. *Bulletin of the American Academy of Psychiatry and Law*, 22, 19–29.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.
- Corrigan, P.W., & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1, 16–20.
- Davis, M., Geller, J., & Hunt, B. (2006). Within-state availability of transition to adulthood services for youths with serious mental health conditions. *Psychiatric Services*, 57, 1594–1599.
- Eisenberg, D., Marilyn, F.D., Golberstein, E., & Zivin, K. (2009). Stigma and help seeking for mental health among college students. *Medical Care and Research Review*, 66, 522–541.
- Ford, T., Goodman, R., & Meltzer, H. (2003). The British Child and Adolescent Mental Health Survey 1999: The prevalence of DSM-IV disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42, 1203–1211.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. London: Aldine Transaction.
- Kaushik, A., Kostaki, E., & Kyriakopoulos, M. (2016). The stigma of mental illness in children and adolescents: A systematic review. *Journal of Psychiatric Research*, 30, 469–494.
- Khadr, S., & Kelner, C. (2008). Transition care - Between a rock and a hard place? *Journal of the Royal College of Physicians of Edinburgh*, 38, 194–195.
- Lapatin, S., Gongalves, M., & Alegria, M. (2012). Lessons from the use of vignettes in the study of mental health services disparities. *Health Services Research*, 47, 1346–1362.
- McGorry, P.D., Hartmann, J.A., Spooner, R., & Nelson, B. (2018). Beyond the “at risk mental state” concept: Transitioning to trans diagnostic psychiatry. *World Psychiatry*, 17, 133–142.
- McNamara, N., Coyne, I., Ford, T., Paul, M., Singh, S., & McNicholas, F. (2017). Exploring social identity change during mental healthcare transition. *European Journal of Social Psychology*, 47, 889–903.
- McNamara, N., McNicholas, F., Ford, T., Paul, M., Gavin, B., Coyne, I., ... & Singh, S.P. (2013). Transition from child and adolescent to adult mental health services in the Republic of Ireland: an investigation of process and operational practice. *Early Intervention in Psychiatry*, 8, 291–297.
- McNicholas, F., Adamson, M., McNamara, N., Gavin, B., Paul, M., Ford, T., & Singh, S. (2015). Who is in the transition gap? Transition from CAMHS to AMHS in the Republic of Ireland. *Irish Journal of Psychological Medicine*, 32, 61–69.
- Merikanagas, K.R., He, J.P., Burstein, M., Avenevoli, S., Cui, L., Benjet, C., & Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication - Adolescent Supplement (NCS-A). *American Academy of Child and Adolescent Psychiatry*, 49, 980–989.
- Paul, M. (2004). Decision-making about children's mental health care: Ethical challenges. *Advances in Psychiatric Treatment*, 10, 301–311.
- Paul, M., Berriman, J.A., & Evans, J. (2008). Would I attend child and adolescent mental health services (CAMHS)? Fourteen to sixteen year olds decide. *Child and Adolescent Mental Health*, 13, 19–25.
- Pescosolido, B.A., Olafsdottir, S., Martin, J.K., & Long, J.S. (2008). Cross-cultural aspects of the stigma of mental illness. In J. Arboleda-Flórez & N. Sartorius (Eds.), *Understanding the stigma of mental illness* (pp. 19–35). Chichester, UK: John Wiley & Sons, Ltd.
- Singh, S.P., Paul, M., Ford, T., & Kramer, T. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multi perspective study. *The British Journal of Psychiatry*, 197, 305–312.
- Tuomainen, H., Schulze, U., Warwick, J., Paul, M., Dieleman, G.C., Franić, T., ... & For the whole MILESTONE consortium (2018). Managing the link and strengthening the transition from child to adult mental health care in Europe (MILESTONE): Background, rationale and methodology. *BMC Psychiatry*, 18, 1–11.
- United Nations General Assembly (1989). *Convention on the rights of the child. United Nations Treaty Series* (vol. 1577, p. 3). Available from: www.refworld.org/docid/3ae6b38f0 [last accessed 9 April 2019].
- Weithorn, L.A., & Campbell, S.B. (1982). The competency of children and adolescents to make informed treatment decisions. *Child Development*, 53, 1589–1598.
- Wrigley, S., Jackson, H., Judd, F., & Komiti, A. (2005). Role of stigma and attitudes toward help-seeking from a general practitioner for mental health problems in a rural town. *Australian and New Zealand Journal of Psychiatry*, 39, 514–521.
- YMCA (2016). *I Am Whole. A report investigating the stigma faced by young people experiencing mental health difficulties*. Available from: <https://www.ymca.org.uk/wp-content/uploads/2016/10/IAMWHOLE-v1.1.pdf> [last accessed 9 January 2019].

Appendix 1

The MILESTONE Consortium: members and partner institutions

Swaran Singh, Helena Tuomainen, Jason Madan, Moli Paul, Cathy Street, Dieter Wolke, Jane Warwick, Priya Tah, Alastair Canaway, James Griffin, Rebecca Appleton, Amanda Tuffrey, Anna Wilson, Charlotte Gatherer, Leanne Walker (University of Warwick, UK); Giovanni de Girolamo, Giulia Signorini, Alessandro Ferrari, Elisa Gheza, Cecilia Ferrari, Laura Rivolta, Flavia Levi, Maria Cataldo, Lidia Manenti, Giorgia Morini, Adriana Pastore, Cecilia Toselli, Pamela Varvara (Saint John of God Clinical Research Center, Italy); Paramala Santosh, Ilyas Sagar-Ouriaghli, Natalie Heaney, Jatinder Singh (Kings College London, UK); Diane Purper-Ouakil, Frédéric Russet, Virginie Maurice, Véronique Humbertclaude (Centre Hospitalier Universitaire de Montpellier, France); Athanasios Maras, Larissa van Bodegom, Mathilde Overbeek (Yulius Academy, Netherlands); Ulrike Schulze, Jörg M. Fegert, Paul Plener, Melanie Saam, Ulrike Breuninger, Renate Schepker, Michele Noterdaeme (University of Ulm, Germany); Sabine Tremmery, Gaëlle Hendrickx (Katholieke Universiteit Leuven, Belgium); Fiona McNicholas, Aleksandra Gronostaj, Rachael McKenna (University College Dublin, Republic of Ireland); Tomislav Franić, Nikolina Davidović (University Hospital Split, Croatia); Kate Lievesley, Federico Fiori (HealthTracker Ltd, UK); Frank Verhulst, Gwen C Dieleman, Suzanne Gerritsen (Erasmus Medical Centre, Netherlands); Andrea Wohner (concentris research management GmbH, Germany).

Accepted for publication: 8 February 2020