Some ethical issues that arise from working with families in the national health service

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Abstract

Through a case study, this paper addresses ethical issues and dilemmas faced by a Family Therapist working in a Child and Adolescent Mental Health Service (CAMHS) in the National Health Service. When there are legal and societal obligations on parents/carers to ensure that the needs of children and young people are met within a family context, working with a young person in a health-care setting oriented to the individual raises ethical dilemmas around consent. When the values of young people and their parents conflict, legal, ethical and political issues can be raised. These have implications for the duties of health care professionals and the rights, interests and autonomy of the individual young people and their parents. The importance of justice to CAMHS practitioners' ethical decision-making about when to prioritize the individual over the family, or vice versa, is emphasized.

Introduction

This paper discusses ethical issues that arose from working with a young person in a Child and Adolescent Mental Health Service (CAMHS) Family Therapy Clinic within the NHS. Whereas most CAMHS consider children as individuals within the context of their families and other environments, the NHS is primarily organized to deliver health care to individual patients. The situation of young people capable of giving consent for their own treatment, while still being considered socially, economically and legally dependent within a family setting, creates complex ethical dilemmas for practitioners offering treatment to such young people and their families.

CAMHS

Community-based CAMHS are specialist mental health services for children and young people up to 18 years of age.[1] Since the case in this article refers to a young person, we will henceforth refer only to young people. CAMHS are staffed by a multidisciplinary mix of clinical psychologists, community psychiatric nurses, social workers, psychiatrists and family, psychodynamic and experiential therapists. Young people are referred to CAMHS when there are concerns about threatened or actual self-harm, mental disorders such as depression or eating disorders, or developmental disorders such as autism spectrum disorders.[1] Assessment, diagnosis and treatment take into account biological, psychological and developmental factors relating to the young person, as well as their family, educational and social support systems.[2] Referred young people are usually seen with their parents or carers. Interventions offered include behavioural, cognitive–behavioural, psychodynamic, family and group-based approaches, as well as psycho-educational and pharmacological therapies.[3]

A contemporary definition of young people's mental health includes a capacity to enter into and sustain mutually satisfying personal relationships, continuing progression of psychological development, an ability to play and

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learn so that attainments are appropriate for age and intellectual level, a developing moral sense of right and wrong, and the degree of any psychological distress and maladaptive behaviour being within normal limits for the individual's age and context.[1] Mental health problems can be construed as difficulties or disabilities in any of these areas that may cause concern or distress. While concepts of mental health, illness and disorder, psychiatric classification and treatment, and the relationship between normality and abnormality (particularly in a developmental context) all court controversy, a discussion of these factors is beyond the remit of this paper.

The aetiology of young people's mental disorders is best described as multifactorial. They should be seen in developmental and environmental contexts[4] and their difficulties as resulting from a complex interplay between the young person, their experiences of their internal world, and the surrounding social and physical environment.[1]

Working with young people in health-care settings[5] and in CAMHS[6] entails many legal and ethical challenges. For example, seeking consent for young people's care is more complicated than seeking consent for adults' care. There is a legal assumption that young people over the age of 16 years can consent. Anyone under 16 with competence can also consent, but the consent of an adult with parental responsibility can be legally valid even in the face of a competent young person's refusal. Young people's rights to participate indicate that proceeding with parental consent alone is not altogether clinically or ethically sound, even if it is legally acceptable.[7,8]

Young people aged 16 or 17 are entitled to the same level of confidentiality as adults, as are young people under 16 who have the capacity and understanding to take decisions about their own treatment. In other instances, the entitlement lies with a person with parental responsibility.[9] There are rare but specific times when confidentiality may have to be breached (e.g. if a young person may be placed at further risk of being abused if confidentiality is not broken).[10] This paper will concentrate on issues of consent and confidentiality in the practice of Family Therapy.

Family Therapy

The family has been described as 'a collection of people, related to each other by marriage, ancestry, adoption, or affinity, who have a commitment to each other and a unique identity with each other... The adults in the collection have varying degrees of responsibility for young members that might be a part of the collection.'[11] 'Family Therapy' can be used to describe a number of different theoretical approaches and bodies of knowledge that address family and other relationships. Interventions can be informed by Cybernetics, Systems Theory, Social Constructionism and a variety of other theories.[12,13] The unifying concept is that human problems can be understood as interpersonal as well as intrapsychic. Family Therapy aims to address relationship difficulties within and between people at a behavioural, cognitive and emotional level. Therapeutic conversations focus on relationships in order to facilitate understanding and reflection about what would be beneficial to individuals within a family, and to the family as a whole. Within the UK, Family Therapists belong to a relatively recently established profession. Accreditation standards require a previous professional qualification at degree level, substantial experience in a mental health or social welfare discipline and a further postgraduate degree in Family Therapy.[14]

In the following case, the family's details have been changed to protect their identity. Discussion about cases such as this could draw on a number of issues, including race, age, social class, sexuality and disability, but we focus on issues of culture, gender, values and beliefs.

The case

Ash, a 17-year-old girl, was referred to CAMHS by her General Practitioner because of self harm, depression and family disagreements. Ash's immediate family consisted of her mother, her father and her two brothers. Ash's parents described themselves as Hindu and of Indian origin. Ash described herself as British and not of any particular religion. Whilst valuing some aspects of her parents' culture, she described being influenced by the multicultural, urban community in which she lived. The case was referred to Family Therapy because the problems were thought to involve family relationships.

Ash's parents accepted the appointment offer but Ash refused to attend. Her parents thought Ash was withdrawn and, having read her diary surreptitiously, were concerned she was suicidal.

The Family Therapist discussed Ash's refusal to attend with her parents and with Ash. Ash's parents wanted to attend for advice. They believed they could insist on Ash attending, even if she was unwilling. Ash did not object to her parents attending, saying 'they probably need it'. She agreed to attend an individual appointment to give her 'side of the story'. She believed she should consent to attend the clinic herself, rather than her parents consenting on her behalf.

At the first appointment, Ash's parents described the problems beginning when Ash attended a local youth club, mixing with young people from different racial backgrounds. Their view was that the parents of these young people had 'no rules or control over their children'. They saw themselves as having learned respect for and obedience to their parents. They felt their views were disrespected and disregarded by Ash. Taking the moral duties of parenthood seriously, they were concerned they were failing both Ash and their community. When Ash became romantically involved with a white boy, they perceived this to be a direct insult to their values. They thought Ash saw them as too strict, as being in the wrong and as less influential than her peer group.

Ash's parents expected to set the rules in their family and felt disempowered by her refusal to attend with them and the therapist's acceptance of this. They agreed to attend Family Therapy and asked for help with discharging their parental duty to influence Ash's moral development by 'correcting' her behaviour. They anticipated that the therapist would inform them of Ash's thoughts and feelings. They chose to ignore the therapist's explicitly stating that she could not impose parental values on Ash. They acted as if the therapist would be able to reinvest them with the power to influence Ash. They expressed relief that Ash had agreed to see the therapist even though it

was on her own terms, in the hope that the therapist could influence Ash 'to do the right thing'.

When Ash was seen on her own, she said 'Anything I say here I don't want repeated to my parents'. The therapist confirmed that, unless there was a significant risk of harm to Ash or others, information from the meeting would be confidential. Ash expressed anger, feeling her parents and General Practitioner had colluded to '... get me to see a shrink'. She said 'I'm not mental, and don't you think I'm mental'. Ash resented her parents for reading her diary and telling her who she could and could not spend time with. She said she had confided her thoughts of self-harm and suicide, and feelings of hatred towards her parents, in her diary as her parents had 'invaded my space'.

Ash disagreed with house rules that, as a female, she was expected to help in the kitchen and keep the house clean and tidy. She said nobody listened to her, cared about her or understood her and that she could not communicate with anyone in her family. She felt lonely and isolated at home, resorting to self-harm as a way of releasing intense feelings rather than because she intended to kill herself. Ash talked of her ambitions to be financially independent, own a house and not marry. She connected her difficulty in communicating with her parents to their wish to control her social life. In principle, she felt family was important and wished to remain in the family; she felt concerned for her parents and wanted to have a better relationship with them. Her feedback to the therapist was that she enjoyed talking to her and it was 'good to talk'.

The therapist offered a series of Family Therapy appointments because she believed she had a duty to act in the best interests of Ash and work towards Ash's safety and continued place in her family. She negotiated a contract to meet with Ash as an individual and with others in her family in different combinations (e.g. mother–daughter, siblings, father–daughter, husband–wife). This was experienced as a helpful way to address the issues. Despite being told repeatedly that Ash's confidentiality would not be breached unless there was a risk of significant harm, Ash's parents held onto a false belief that the therapist would tell them what Ash said in therapy. This meant accepting that Ash's parents would attend therapy sessions on a false premise. On the other hand, allowing family members to think separately about what would be useful to share and what needed to remain private and confidential to individuals facilitated the strengthening of family relationships.

In ensuing sessions, the therapist accorded respect to the different views held by Ash and her parents simultaneously. For example, she acknowledged that Ash's parents' view of being good parents arose from their own experiences of being parented; their conviction that it was their moral duty to guide their daughter's emotional and social life; and their obligation to uphold their social and community values. She also acknowledged Ash's view that it was unreasonable of parents to control their children's choice of friends. The therapist held in mind both perspectives on how 'to do family relationships'. She learnt about the underlying feeling in the family that the misunderstandings, lack of respect and disharmony were leading to a breakdown in communication and that, without external input, this situation was unlikely to resolve.

Within the protected environment of therapy, Ash's mother talked of her experiences of being mothered. She had wanted a closer relationship with her mother and had promised herself that she would be closer to her own daughter. Ash was not aware of her mother's good intentions, perceiving her mother's actions to be overprotective and interfering. When mother and daughter agreed to a joint session and shared this information, different cultural understandings emerged, enabling Ash to understand why her mother focused so much on her. Further discussions about the role and expectations of women in the family enabled changes to take place in the way the family related to each other.

Discussion

Justice

The first ethical consideration for the therapist was whether to see anyone in the family when Ash was refusing to attend. The bipartite decision-making partnership between patient and health-care professional becomes complicated in Family Therapy because, although young people are referred as individuals, they usually have at least one parent or carer: the decision-making partnership thus becomes tripartite. Consent can only be given by individuals, not groups. In this case, therefore, the question arose as to who should give consent.

In legal and NHS contexts, the first question is whether a referred person can give consent. As Ash was over 16 years of age, there was a legal assumption that she could give consent.[15] This influenced the therapist to contact her to establish whether her refusal was absolute or negotiable. In this case, Ash consented to attend an individual initial assessment appointment. By not raising an objection to her parents being seen in their own right, she saved the therapist from another ethical dilemma: whether or not to see parents in the face of a refusal to consent by the referred individual.

When, as is often the case, the interests of the referred individual and other family members coincide, identifying distinct duties to individuals may be pointless. Sometimes, however, interests do not coincide, and prioritizing one family member's interests or values may entail disadvantage or even harm to other family members. In this case, respecting Ash's liberal values could be perceived as undermining her parents' communitarian values. Under such circumstances, health-care professionals often deliberate about who can give legal consent. This can be unhelpful, as the real issue is one of justice; namely whose interests, rights or values ought to take priority.[16]

Duty of care

The next ethical dilemma confronting the therapist was whether she owed a duty of care to Ash's parents, regardless of whether Ash consented to attend. They wanted help for themselves, whether Ash attended or not. CAMHS often receives referrals about young people because of parents' or professionals' concerns, rather than those of the young person. Sometimes, the person who has the primary problem is not the referred young person,

whose symptoms are a consequence of relationship difficulties at home or at school.

If, ethically, a duty of care arises from the 'special' health-care professional–patient relationship, the clearest duty is to the referred young person. What is not clear is whether parents and siblings of the referred individual count as patients, especially when there is a conflict of interests. Parents may be brought within this special relationship when they act as their young person's proxy decision maker, advocate or representative. In this case, Ash did not need a proxy decision maker and would not have chosen her parents as her representative or advocate.

It could be argued that a duty of care to the young person implies a duty of care to their family because supporting the family is good for the young person. If so, then parents and siblings have rights, although it is unclear what sort of rights they have and whether they can claim that clinicians should act for their benefit. The therapist in this case decided she did have a duty of care to Ash's parents because they had serious concerns about Ash's mental health. Legally, parents have not only the responsibility but the right to access appropriate health care on behalf of their children. Thus the State's agencies, including the NHS, have duties to support parents with this task.[17] Most codes of ethics are based on individualism and offer little real guidance for working with different parts of a family.[18] The *Code of Ethics and Practice* published by the Association of Family Therapy states that Family Therapists must act with honesty and integrity to 'promote the welfare of families and individuals' and when faced with an ethical dilemma 'should adopt the course of action which '"maximises the good and does the least harm", attaching particular weight to the rights of those who have least power'.[19] Informed by the belief that everyone in the family is one's client, the therapist felt ethically she had a duty of care to Ash's parents. An assessment appointment was therefore offered to the parents, regardless of Ash's initial refusal.

Rights and interests

Alderson describes three approaches to young people's rights: 'parentalist', 'libertarian' and 'interventionist'.[20] We will consider the case in relation to these positions.

Parents' rights to decide on behalf of their children have been justified in terms of the importance of preserving intimate family relationships, with minimal State interference, within liberal societies. Within such models, parents decide what is in the best interests of the family (parental autonomy) rather than considering the individual young person's best interests, although the young person's best interests are said most often to follow from this arrangement.[21] Parents' and young people's rights to privacy and family life are legally confirmed in the UK by the Human Rights Act 1998.[22]

Goldstein *et al.* used the phrase 'family integrity' to encompass three interests of relevance to young people: parental autonomy, the right to have autonomous parents, and privacy.[23] Whilst firmly parentalist, an understanding of child protection and a psychodynamic theory of child development are at the heart of their theory. Ross promotes the notion of families as intimate groups, valued for their child-rearing functions and their intimacy.[24] Within such groups, other-regarding activities become self-regarding activities and the interests of the family amount to more than the sum of its individual members' interests. Ross' model of constrained parental autonomy does not use the best-interests model applied to each individual young person alongside parental autonomy, but permits parents to make intrafamilial trade-offs as long as each child-member's basic needs are met. Indeed, libertarian parentalists would argue that theories that formulate the function of families as solely for child-rearing ignore the rights of adults to have a family life within which their own interests and values flourish.

Certainly, Ash's parents felt their religious and cultural values should flourish in their family. They also felt their interests, whether as good parents or good members of their religious and cultural community, were being undermined by Ash's behaviour and attitude. They were endeavouring to meet Ash's basic needs by seeking help in managing her self harm and suicidal thoughts. Ash valued the intimate nature of her family: the problem for the therapist was that Ash and her parents did not have a shared view of Ash's interests (e.g. Ash's parents thought mixing with young people outside their culture was not in Ash's interests, while Ash thought the opposite). Far from dealing with the 'sum' of individual family members' interests, the therapist was caught in the difference.

Libertarians, who are often young people's rights proponents, argue that seeing young people's interests in the context of family interests is to deny the importance of young people as individuals, to fail to respect their autonomy and to treat them as property rather than people, perpetuating the imbalance of power in families in favour of parents.[25] Ash identified her interests as remaining in her family and being part of an urban, multicultural youth community. The difficulty was that her interests clashed with her parent's interests in maintaining their, and her, place in their community.

Interventionists are usually thought of as professionals with interests in young people's welfare. Health-, social care- or education-based professionals often have statutory responsibilities for young people's protection, care and development. They tend to be wary of making the threshold of intervention too low (i.e. lower than that necessary to protect young people from abuse, neglect or even inadequate nurturing). In extreme situations, professionals may intervene against the wishes of young people or parents. In this case, following the initial discussions and assessment, both Ash and her parents wanted the intervention.

CAMHS in the UK exist in a state of tension between these three different perspectives. Whilst being essentially interventionist in nature, and interacting with young people practically, legally and theoretically in the context of their families and wider systems, CAMHS exist in a country where individual-oriented, libertarian concepts dominate law, health care and society. CAMHS professionals' ethical reasoning should therefore take into account all three perspectives, and this can result in ethical dilemmas. In this case, the therapist had to relate to Ash as the referred patient in a number of ways: as an individual, as a family member, as an individual in therapy, and as a patient within the NHS. In order to practice ethically, the therapist had to decide which aspect of these relationships to prioritize and in which order.

The therapist first took an interventionist perspective and prioritized the relationship with Ash within the NHS. Working in a service commissioned to address the mental health needs of young people, in which the prevention of suicide is a high priority, she applied the principle of non-maleficence and worked towards the prevention of self harm and possible suicide.

The therapist then took a libertarian perspective, in line with the law and government guidance on consent, and prioritized Ash as an individual. She applied the principle of respect for autonomy when she continued to explicitly state that Ash would have to choose to come to family sessions and individual sessions, despite her parents feeling disempowered by this approach.

The therapist also took a parentalist perspective when she offered Ash's parents an intervention, regardless of Ash's consent or refusal. In doing this she acknowledged the parent's rights to access services in the interests of their young person and in their own interests.

Autonomy

CAMHS professionals deal with the dilemmas of adolescence, which can be said to be a transitional state between childhood and adulthood. There are greater legal and political rights to self-determination when one reaches legal majority. Ethical deliberations about patients who are clearly dependent young people and those about clearly independent adults (usually including young people over 18 years of age) are less taxing than those about young people who are capable of being ethically, cognitively or socially autonomous but are still dependent on their parents in legal, social or relational terms. In dealing with the latter type of young person, exemplified by Ash, CAMHS professionals face more complex ethical dilemmas, often involving considerations of autonomy and respect for autonomy.

Consistent ethical deliberations about autonomy require an understanding that autonomy is not one concept, but rather one word that has different meanings. These different meanings are associated with differing developmental, philosophical and political theories: for example, autonomy is used synonymously with independence, freedom, competence, self-determination, personhood and in the context of rights. The differing theories have different implications in terms of when to respect whose autonomy. In CAMHS, professionals may be more likely to think of autonomy in developmental terms (i.e. as an aspect of psychosocial development that emerges from a mix of maturational, social, and psychological changes).[26] This understanding of autonomy has implications for some ethical notions of autonomy[27] (e.g. autonomy as a psychological disposition to make rational choices) but not others (e.g. autonomy as a right). Indeed, autonomy as a right stems from the principles of liberty and respect for people and, as such, is more a rule about how we treat people, and whether we accept their rights claims, than about the attributes of the individual.[28]

Values

The discussion about confidentiality in the initial meetings with Ash and her parents raised ethical dilemmas about their differing values. How could the therapist respect two mutually exclusive sets of values with two different expectations about confidentiality? Ash's parents expected the therapist to tell them what Ash said and Ash expected the therapist not to tell her parents what she said. The therapist again dealt with this by considering which relationship to prioritize when. As the referred patient, Ash's individual valuing of privacy was acknowledged and her confidentiality respected.

Throughout the process of therapy, the therapist's perspective was informed by a complex set of factors, including her theoretical orientation and the unique circumstances of the family. An additional ethical challenge for the therapist was to manage the interplay between her own cultural values and beliefs and those of her clients.[29] The therapist's personal and professional values certainly had an impact on the therapy (i.e. the parents thought the therapist was aligned with Ash because of their shared belief in the rights of the individual). Ash's parents held more community- and family-oriented values, expecting that they would have the final say about what was best for their daughter and that the therapist would tell them what Ash said so that they could carry out their parental and community duties. Ethically, freedom from intrusions into one's privacy and respect for autonomy, both constructs oriented towards individuals, informed the therapist's decisions to respect Ash's rights of confidentiality and seek Ash's consent to her own attendance at CAMHS.

Conclusions

When working with young people, CAMHS professionals must take families, and parents in particular, into account when thinking of their duties of care. Acknowledging the libertarian, parentalist and interventionist perspectives intrinsic to working at CAMHS can help to explain the ethical reasoning of such professionals.

Ethical dilemmas can be faced when therapists' values differ from those of the families they see, or when family members' values differ. Exploration of values in therapy can facilitate greater understanding and change within families.

CAMHS professionals face different and more complex ethical challenges when their adolescent patients are capable of being autonomous but are dependent on their parents in legal, social and relational terms, which limit their exercise of certain types of autonomy. This has implications for CAMHS professionals' capacity to respect young people's autonomy while addressing their difficulties in a family context.

CAMHS professionals often need to decide whether to prioritize the interests, rights or values of the young people they see or those of their parents. This involves specific ethical consideration of justice. The seeking of consent to treatment is a parallel issue and should not be conflated with such issues of justice.

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