Talk About Self Harm (TASH): Participatory Action Research with young people, GPs and Practice Nurses to explore how the experiences of young people who self-harm could be improved in GP surgeries

Running head: Talk About Self Harm (TASH): Participatory Action Research with young people who self harm

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MeSH compliant key words: Adolescent, education, general practice, identification, self-injurious behaviour.

Key Messages:

- Primary care has an important role to play in treating young people's self-harm.
- Young people present to their GPs surgery with different patterns of self-harm.
- Young people, GPs and Practice Nurses welcome self-help materials.
- Further research is needed to test self-help interventions for self-harm.

Abstract

Background: The incidence of self-harm in young people in primary care is increasing dramatically and many young people who self-harm visit their GP surgery as a first point of contact for help.

Aim: To explore with young people, GPs and Practice Nurses; 1) why young people present with self-harm to primary care and 2) whether young people, GPs and Practice Nurses can take steps to have more helpful consultations about self-harm in GP surgeries that include self-help materials developed by young people being used to support such consultations to take place.

Design and setting: Participatory action research with GPs, Practice Nurses and young people employed mixed methods to collect statistical and narrative data.

Methods: Statistics from 285 young people's medical records were captured including more detailed analyses of a random sample of 75 of these records. A series of 24 focus groups with a total of 45 GPs, Practice Nurses and Young People, with an average number of 8 participants in each group were conducted. Statistical data was subject to descriptive and inferential analyses and thematic analysis was applied to the transcripts from the focus groups.

Results and conclusion: The type of self-harm young people presented with influenced whether they would see a GP or Practice Nurse. While self-help materials were welcomed and deemed helpful, young people, GPs and Practice Nurses were ambivalent about using these in

short consultations where time was an overriding constraint. More research is needed on the feasibility of adopting self-help assisted interventions in GP surgeries.

Keywords: Child and Adolescent Development, consultation, doctor-patient relationship, health promotion, mental health, Primary care

INTRODUCTION

The incidence of self-harm in young people in primary care in the UK is increasing dramatically [1] and many young people who self-harm meaning, "deliberately initiated behaviour (such as self-cutting or ingesting a toxic substance or object with the intention of causing harm to oneself with a non-fatal outcome)" [2], visit their GP as the first point of contact for help [3,4]. Incidences of self-harm are of international concern [5].

UK clinical guidelines identify primary care as having an important role to play in preventing, assessing and treating self-harm [6] and GPs see the identification of self-harm in young people as part of their role [7]. Yet there are barriers encountered by young people that influence whether they will seek and receive help from their GP surgery. Pragmatic barriers arise from the practice setting such as short consultation times that militate against clinicians building rapport with a young person [3, 4]. Interpersonal barriers relate to clinicians' confidence in talking about self-harm for example GPs often report voicing concerns about what language to use when raising issues of self-harm [7, 8] and young people themselves present as a heterogeneous population with differences in their ability to identify and describe emotions [8]. Assessing the risks associated with young peoples' self-harm is a challenge for primary care clinicians [9]. For some young people self-harm will be low risk and transient and/or a response to normal developmental stressors (such as bullying and/or exam pressures) [10]. Clinicians will encounter gendered risks, for example over one third of girls who present with

self-harm have a diagnosis of depression while in boys ADHD and autism spectrum disorders are more common [1]. Rates of young people's self-harm also vary depending on their social circumstances, with rates highest in deprived areas, 27.1 per 10,000 compared with 19.6 per 10,000 in areas of least deprivation [1]. Risk factors include substance misuse, personality problems and/or suicidality with drug overdose being a common method of self-harm in 83% of cases [1, 3, 11]. Young people's self-harm however presented, requires effective screening, diagnosis and treatment that involves the primary care clinician.

AIMS

Given the challenges identified above the aims of the Talk About Self-Harm study were to explore with young people, GPs and Practice Nurses; 1) why young people present with self-harm to primary care and 2) whether young people, GPs and Practice Nurses can take steps to have more helpful consultations about self-harm in GP surgeries that include self-help materials developed by young people being used to support such consultations to take place.

METHODS

Participatory action research is widely used in the social and health sciences to facilitate empowering and emancipatory experiences for research participants, who are the main beneficiaries of the intervention [12]. PAR is founded on principles of inclusivity [13] and is suited to working with vulnerable populations (such as young people who self-harm) where negative attitudes (from clinicians) may be part of the problem, requiring a change in approach [14].

PAR relies on the collection and analysis of data through an iterative process which distinguishes it from mixed methods studies that are linear in design. The latter was exemplified in this study through the inclusion of a steering group with clinicians, practice managers, from

the GP surgeries that took part, and researchers alongside an expert reference group involving young peoples' organisations. Both groups influenced the study design and data collection methods, and both were involved in the dissemination of findings to stakeholders [15].

PAR also accords with the modern NHS aspiration in the UK, reflected in policies that call for "no decision about me without me" [16] thus supporting young people's involvement in contributing knowledge and experience alongside that of GPs and Practice Nurses about what improved outcomes from seeking help for self-harm should look like from their perspective. As such this study extends previous research with GPs [4] and to our knowledge is the first time that PAR has been used in a general practice setting.

Figure 1 illustrates how the three phases of PAR - planning, action and critical reflection - occurred concurrently, providing opportunities to learn from statistical data obtained from a survey of 285 patient records relating to young people with self-harm [17] and narratives captured from a series of focus groups with young people, GPs and Practice Nurses.

Insert Fig 1 here.

Statistical Data Collection

A protocol to collect statistical data from young peoples' medical records was designed by the Project Steering Group (PSG) that included representatives from each GP surgery taking part in the study. Statistics included baseline data relating to a young person's most recent presentation of self-harm (Stage 1). All electronic patient records for young people aged 16-25 years in the participating GP surgeries were searched to identify those with a primary EMIS code relating to self-harm (n=285). Using the sample size calculator from the Clinical Audit Support Centre [18] a random sample of 75 of these records were selected for Stage 2 analyses which captured more in-depth data about presentations and referrals for self-harm during the 4 months prior to the young person's most recent episode. This sample size was agreed with the

PSG, with the 4 month period being deemed long enough to allow for records of repeat self-harm to be captured as well as information on referrals and any follow up from more specialist mental health services.

Focus groups

Focus Groups – Staff

Staff volunteered to take part in focus groups with at least one focus group (FG) occurring in each phase of PAR in each practice to facilitate the ongoing participation of clinicians. Practices chose whether the focus groups were conducted with GPs and Practice Nurses together or separately to maximise the number of staff engaging in the study, while managing the logistics of fitting in the focus groups between busy surgeries

Focus Groups – Young People

Young people (YP) with experience of self-harm were recruited through a snowball sampling approach beginning with the introduction of the project to the agencies represented on the Expert Reference Group (ERG). Three young people with experience of self-harm came forward to participate. These young people then approached others they knew within the 16-25 age range with similar experiences of seeking help from their GP surgery for self-harm. The focus group topic guides were informed by emerging themes from the analyses of medical records, and the challenges of help-giving that had been raised by GPs and PNs in initial focus groups. Some groups were task focused (for example reviewing/creating the self-help materials) while others reflected more fluid discussion about young peoples' help seeking experiences at their GP surgery.

Focus groups in each phase of the PAR process ran concurrently with young people and clinicians, to reflect on the emerging data and explore how and whether short, primary care consultations could be tailored to support young people to manage their self-harm in better ways with the aid of self-help materials.

Participants

Three, multi-doctor GP surgeries were purposefully selected to take part in the study. They were geographically close to two universities so there was a high degree of certainty that young people aged 16-25 featured in their patient populations. The three practices also served different patient populations with one being in a more affluent area and the other two surgeries covering several neighborhoods ranked among the 10% most deprived in the country [19].

14 GPs, 16 PNs and 15 young people aged between 16 and 25 took part in the focus groups as a self-selecting sample, with a mix of gender and ethnicity (see Table 1).

Insert Table 1 here

Analysis

Statistical data were analysed using IBM SPSS Statistics Version 24. Chi Square was used to compare the pattern of self-harm, type of self-harm and referral rates between males and females. ANOVA was used to assess differences in the frequency of GP and Nurse consultations.

Narrative data were analysed by the lead researcher (DB) using inductive thematic analysis which involved coding and the identification and clustering of themes. Reliability was achieved

by the Research Fellow (LK) analysing the transcripts separately, followed by a joint discussion to arrive at a consensus about overarching themes and sub-categories [20].

Results

Recruitment resulted in 13 staff focus groups taking place across the three GP surgeries and spanning the three PAR phases with an average of 8 clinicians attending each group. Eleven focus groups across the three PAR phases were conducted with young people with an average of 7 young people attending each one.

The results from the survey and focus groups are combined and presented under three themes supported by the statistical and inductive analyses.

Theme 1: Type and pattern of self-harm influences consultation experience

From the statistical analyses of medical records 285 young people with a mean age of 21.17 years (*SD* = 2.22) were identified as having had at least one episode of self-harm (female *n* = 205, male *n* = 80). These young people presented with a total of 630 individual episodes of self-harm yet information about the type of self-harm was only recorded for 465 of these episodes. The most common type was intentional self-harm harm/intentional self-harm by sharp object (*n* = 271, 58.3%). Other types of self-harm identified were overdose/self-poisoning (*n* = 114, 24.5%), thoughts of intentional self-harm (*n* = 64, 13.8%) and suicide/attempted suicide (*n* = 16, 3.4%).

A chi square analysis revealed a significant difference in the type of self-harm between males and females χ^2 (3) = 15.32, *p* = .002. *V* = .18 with males engaging in less intentional self-harm/intentional self-harm by sharp object 42.6 % (*n* = 43), compared with females 62.6% (*n* = 228). Males however were more likely than females to take an overdose/self-poisoning (33.7 %, *n* = 34) compared to females (22%, *n* = 80). Episodes of suicide/attempted suicide

were also more evident in males (6.9%, *n* = 7) compared with females (2.5 % *n* = 9). Thoughts of self-harm were similar amongst males (16.8%, *n*= 17) and females (12.9%, *n* = 47). The findings are demonstrated in Figure 2.

Insert Figure 2 here.

The type of self-harm being presented to GP surgeries reportedly influenced whether young people were seen by their GP or PN with the latter group concurring that they would see young people with cuts or in a minority of cases burns, to dress wounds. In contrast GPs said "we tend to see young people when they have taken an overdose or need a prescription for medication" [FG2]. Practice Nurses agreed that they see young people more often for other reasons such as inoculations, and/or pill checks and it is during these consultations that "you see the scars from self-harm" [FG2]. PNs also acknowledged that in these circumstances they were ambivalent about asking the young person directly what had happened and said that although they would give the young person a chance to talk "it's what you do say if they say something that's serious. I would get a doctor" [FG6]

Young people however, were not party to the clinical deliberations outlined above and expressed a degree of frustration which they attributed to being referred to a PN instead of their GP. One young person suggested that their GP didn't "really want to pay us much attention" while another in the same focus group said "When I try to see my doctor they always refer, just send me to a nurse instead of the actual GP which is annoying because he is my GP and he is supposed to be able to see me" [FG8]. When GPs were supportive this was considered especially important by the young person "I would say that my doctor's better than the mental health services… I'll see my doctor and it's like she'll talk to me about everything" [FG9].

Analyses of young people's medical records in Stage 2 revealed that females had significantly more consultations with a PN during the 4 month period (M = 0.55, SD = 1.02) than males (M = 0.12, SD = 0.33). $t(58.06) = 2.46$, $p = .02$, $d = 0.57$. This gendered experience is likely to be accounted for by females engaging in more intentional self-harm (cutting) and/or presenting to GP surgeries for sexual health related consultations.

From this random sample of young people's records scrutinised in more detail 29 young people were identified as engaging in a one-off episode of self-harm compared with 33 young people whose self-harm was recorded as recurrent. A chi square analysis revealed a significant different between males and females χ^2 (1) = 3.94, p = .05. V = .25 with significantly more females (61.9 %, n = 26) engaging in recurrent self-harm compared to males 35% (n = 7). Whether young people were referred to specialist mental health services was not found to be significantly different between those with recurrent self-harm and those with a one off episodes of self-harm, χ^2 (1) = 1.09, p >.05. V = .13.

GPs discussed the complexities of young people presenting with recurrent self-harm for example in FG3 one GP said "They take up a lot of time, they are not one offs" and another gave an example of trying to work responsively within the constraints of short consultations "Mental health disorders often come in a 10 minute consultation and it often takes 20 minutes. When you are at 15 minutes perhaps we might not have made time for that question but I think now many of us do".

Further analyses of records in Stage 2 using a one-way independent measures ANOVA showed a significant difference in GP consultations F (5,22) = 7.28, p =.001, η^2 = .68. .Post hoc analysis with Bonferroni corrected t tests, indicated that young people whose medical record cited alcohol/drug use as a reason for self-harm had significantly more GP consultations than

those whose records cited relationship/family problems (p =.001, d = 5.24), social anxiety (p =.005, d = 3.79) or academic stress (p =.004, d = 4.44).

Theme 2: Young people often have several reasons for their self-harm so they and clinicians are concerned about disclosure of the behaviour

Reasons for self-harm

The reasons young people gave for their self-harm were only recorded in 29 out of the 75 records in Stage 2 as one GP commented: "I don't always ask them why they do it but if you do ask them they will say it makes them feel better" [FG3]. Further analysis of the 29 records provided evidence that young people often give more than one reason for their self-harm with 36 reasons being identified in total that fell into 6 main categories; Relationship/family problems (22.22%), Academic stress/stress (22.22%), Alcohol/drug use (13.89%), Social anxiety (13.89%), Difficulty managing another illness (11.11%), Low mood (11.11%) and Abuse (5.56%). Clinicians were aware that young people self-harmed for multifarious reasons and acknowledged "many have such complex issues" [FG7]. Young people agreed that sometimes they felt that the reasons given for their self-harm were dismissed by the GP or PN "I think they [clinicians] can be thinking like…what problems can you have 'cause you're, what, fifteen or something but no one knows what is happening at home" [FG8] and one young person explained that their moods and ability to cope with problems fluctuated: "my moods were different. I felt happy in myself for some points, sad at other points whereas the six months before that I was … alone, depressed and not just, wanted to be around" [FG8].

Concerns about disclosure

Young people talked about their fears of disclosing self-harm to a GP or PN in case they were considered "crazy" and/or as one young person put it, "I was scared to talk to the doctor….I just didn't feel confident enough" [FG9]. GPs and PNs also reported lacking confidence to

know whether to raise the issue of self-harm with the young person directly because; "You don't want to open up a can of worms" [FG1] and whether by "asking a young person about their self-harm, do you risk making it worse?" [FG7]. Despite their concerns about disclosure young people reflected that being asked about their self-harm was ok provided that it was asked about in an empathic way. They were able to suggest some helpful ways into such a conversation for example: "Just sort of reassure you that it's gonna be ok", another young person added; "say to you no matter what you're going through there is people there that can help" [FG8].

Theme 3: Interventions for self-harm and potential for use of self-help materials in GP surgeries

In the sample of medical records surveyed at Stage 2, 62 young people had referral information detailed. Half of these young people (n=31) had been referred to another service due to their self-harm and the other half had not. Five of the young people not referred were already involved with another service when they presented to their GP surgery with self-harm. The numbers of males and females being referred was not significantly different, χ^2 (1) = 0.00, p >.05. V = <.001 and neither were referrals for young people with recurrent self-harm significantly different to referrals for those with a one off episode, χ^2 (1) = 1.09, p >.05. V = .13. These findings suggest that for some young people the help they receive for their self-harm will be exclusively provided by their GP surgery. This was explored in the focus groups and GPs explained that this was often the case when they were prescribing medication for depression that co-presented with self-harm. One GP illustrated how they would talk with a young person: "You might want to look at this [referring to self-harm]. This is part of your depression or your anxiety but look you're on the first couple of rungs and there's a whole ladder beyond here" [FG3]. Young people recognised that medication for low mood might be

helpful but as one young person advocated this should be within a range of interventions, a suggestion with which others agreed "there should be like a set procedure to be honest, like, step one, if … that doesn't work … two, three, four, then, last resort, it's on medication" [FG9].

During the course of the project young people sourced and/or created self-help materials for use in GP surgeries to help them manage their self-harm more effectively; for example a blog site, a short DVD about going to the GP with self-harm, a conversation guide for PNs, paper based distraction activities, coping tools and information leaflets. In an early focus group clinicians agreed that they never gave out self-help materials so once these had been developed they were provided to clinicians as a pack with a demonstration of the blog site and the DVD. GP and PNs were eager to use the materials but still felt constrained by the amount of time available to them in consultations to do this: "Consultations are too short to go through information at the time" [FG6] and "It's unrealistic to give information and have a conversation" [FG4]. Young people tended to agree with this: "Ten minute slot it's quite short and then the doctor feels rushed" [FG9]. Double appointments were tentatively suggested by all as a way forward. These already operated to some degree in the practices and young people had experienced these as helpful; as one young person put it; "You've got more space and you won't feel rushed through it. I think that's useful" [FG8]. In terms of using the self-help materials young people suggested that they could act as a conversation prompt when GPs or PNs were not sure what to say when a young person disclosed self-harm for example; "I'd say like obviously get them out and look at them with the young person together" [FG9]. Importantly young people wanted information that they could revisit after the consultation, as one young person advocated; "Like it's good if you talk it through with them and then let them have something they can look at home" [FG8].

Discussion

Young people present with self-harm to primary care for multifarious reasons that reflect personal circumstances, intersect with characteristics such as gender, and are manifest in degrees of risk for example one-off or repeat behaviours. The findings from this study suggest that whether and/or how young people's self-harm is recorded in their records is also subject to variation. This has implications for the accuracy of statistical data used in related research for example cohort studies [21] that rely on databases generated from patient related information entered by general practice staff.

PNs report experiences similar to those of GPs recounted in previous studies [4, 8] in terms of the extent to which they feel confident and competent to engage young people in conversations about their self-harm. Taken together these pragmatic and interpersonal barriers may inadvertently lead to an unintended neglect of young people's self-harm and its aetiology. This becomes an important consideration in relation to the effective management of risk. Joiner argues that the opportunity for prevention and intervention particularly in relation to suicidality lies with 'belongingness' as a protective risk factor, manifest through the social connections in those who self-injure [22]. Given that repeat self-harm is considered a risk factor for suicide [23] any helpful connections made with a young person when they present to their GP surgery are significant in this regard.

The young people, GPs and PNs alike who participated in this study were interested and engaged with self-harm as a mental health issue from the outset and were keen to use self-help materials to promote more helpful conversations. Yet all acknowledged the difficulties presented by the time limited consultations that have been alluded to in previous research by GPs [4]. NICE guidelines advocate that self-help strategies should be promoted alongside treatment interventions for depression and associated self-harm [6] and evidence from the statistical data suggests that in terms of the latter, such interventions are being provided in GP

surgeries, often without recourse to specialist mental health services. Whether and how self-help materials could augment these interventions remains to be demonstrated and further research is needed to test the feasibility of self-help interventions in terms of benefits during and following consultations in GP surgeries.

The strengths of this study lie in presenting new knowledge of identification of personal and cultural phenomena concerning self-harm behaviours in young people and the clinicians they encounter in primary care. PAR is criticised for assumptions about achieving change through research and the illusion of neutrality [24], yet PAR as a methodological approach is receiving growing interest in health inequalities research [25] as a means of emphasising capacities for collaboration to create new knowledge and culture. As the titular acronym suggests, PAR allowed for participation and reflexivity to occur that demonstrated young people as patients, with GPs and PNs had a good and shared understanding of this health issue; a phenomenon not new in the health inequalities literature more broadly [25]. The challenge that remains is having recognised this collective understanding, how [26] it can contribute to improved help giving and help seeking experiences situated within a 'shared world view' that demonstrably delivers better health outcomes [27].

Conclusion

The types of self-harm with which young people presented to their GP surgery influenced whether they would see a GP or a PN and individual clinicians differed in their reported confidence and competence when dealing with young peoples' presentations. While self-help materials were welcomed and deemed helpful by all participants, all were similarly ambivalent about how these could be used in short consultations when time was an overriding constraint. This shared experience is reflected in how young people and primary care clinicians talk about

self-harm and offers a starting point for future research that seeks to deliver better health outcomes for those with this complex mental health issue.

ETHICS: NHS Ethical approval. NRES Committee East Midlands – Nottingham 1 and Nottingham Trent University, College Research Ethics.

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Figure 1: Participatory Action Research Approach

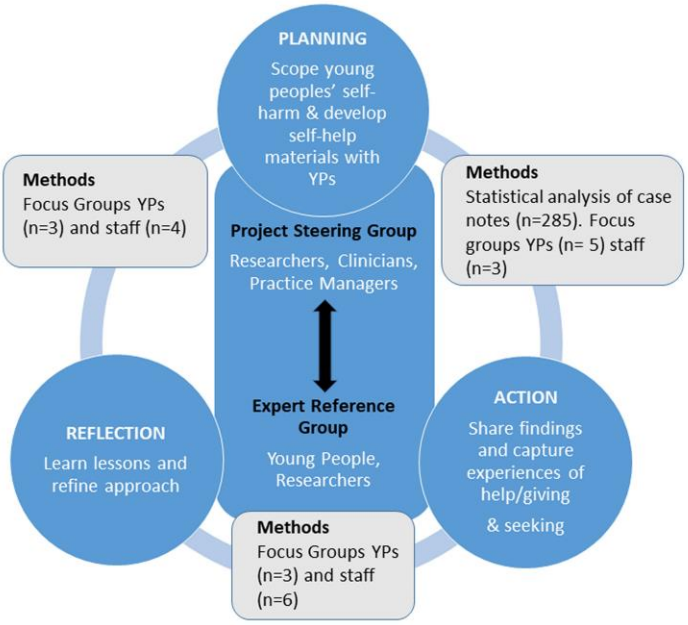

Figure 2: Type of self harm

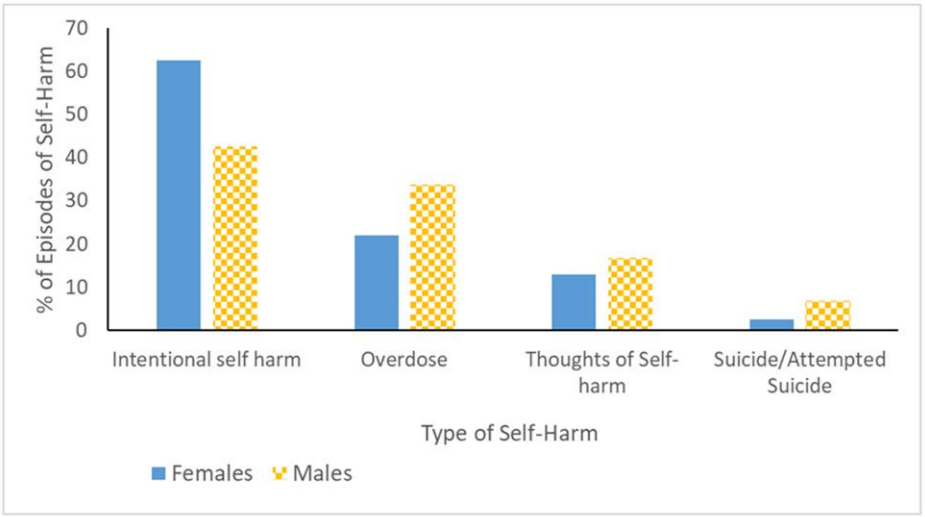

Figure 2

Table 1: Participants taking part in the focus groups

	GPs	**Practice Nurses**	**Young People**
Asian female	3		
Asian male	3		
Mixed race male			1
White female	3	16	7
White male	6		7
Total	**14**	**16**	**15**