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PRIORITISING YOUNG PEOPLE'S EMOTIONAL HEALTH SUPPORT NEEDS THROUGH PARTICIPATORY RESEARCH

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Accessible summary

What is known on this subject

- Young people's mental health is a concern to people around the world. Good emotional health promotes mental health and protects against mental illness, but we need to know more about how to help young people look after their emotional health.
- We are learning that research is better if the public are involved in it, including children and young people. Therefore, we need to listen carefully to what young people have to say.
- In this paper we describe some research that involved young people from start to finish. We were asking what kind of emotional health support would be useful to them.

What this paper adds to existing knowledge

- We developed a useful way to involve young people in research so their voice can be heard.
- Young people like to use the internet to find emotional health support and information, but need to know which websites they can trust.

Implications for practice

- Our method of bringing young people together to tell us their views was successful.
- It is important to explore ways to help young people judge the quality of emotional health websites.

Abstract

Introduction: Youth mental health is a global concern. Emotional health promotes mental health and protects against mental illness. Youth value self-care for emotional health, but we need better understanding of how to help them look after their emotional health.

Participatory research is relevant, since meaningful engagement with youth via participatory research enhances the validity and relevance of research findings and supports young people's rights to involvement in decisions that concern them.

Aim: We aimed to develop a participatory approach for involving youth in research about their emotional health support preferences.

Method: Our team included a young expert-by-experience. We developed a qualitative, participatory research design. Eleven youth (16-18 years) participated in focus groups, followed immediately by a nominal group exercise in which they analysed the data, thus enhancing methodological rigour.

Results: This process highlighted youth perspectives on self-care strategies for emotional health.

Discussion and Implications for Practice: Our simple participatory research approach generated trustworthy and credible findings, which accurately reflect youth perspectives and are consistent with the literature, endorsing our method. Young people said that they want reassurances of quality and safety when accessing digital mental health resources. These findings can inform future development of youth-oriented digital mental health resources.

KEYWORDS

Adolescent
Internet
Mental health
Participatory research
Public participation
Self-care

RELEVANCE STATEMENT

Participatory research is relevant to promoting young people's emotional health because it generates credible and trustworthy knowledge that can be translated into interventions development. We developed a useful participatory approach for bringing youth together to explore collective views about their emotional health needs. Acting as co-researchers, the young people produced a set of principles and solutions particularly relevant to their self-care in relation to emotional health. They identified that they may need reassurance of quality and safety when accessing digital tools for emotional health. This implies a need to explore strategies for establishing the quality and safety of such resources.

INTRODUCTION

This paper describes a participatory research approach with a group of urban young people in the United Kingdom (UK). The aim of the research was to understand young people's views and priorities regarding emotional support needs in this age group. We know that 10-20% of children and adolescents worldwide experience mental disorders, making them vulnerable to long term mental and physical health difficulties, with consequent reduced life chances and quality of life (World Health Organization (WHO), 2016). UK public health statistics reflect the global trend, showing worryingly high prevalence in UK high school students (11-16 years) of: subjective unhappiness (10%); frequent low mood (33%); and being adversely affected by bullying (25-33%)(Green et al., 2005). Longitudinal research studies linking childhood emotional health difficulties with mental illness in adulthood suggest that preventive and protective interventions may be key to improvement (Copeland et al., 2014; Read and Bentall, 2012). Youth participatory research makes a positive contribution to knowledge (Mill and Ogilvie, 2003; Percy-Smith, 2010). It can address

unhelpful power relations in child and youth services (Mason, 2015), enabling an enhanced sense of agency that may also help to build emotional resilience (Hart et al., 2007). Thus, the methodology may itself have a role in promoting emotional wellbeing (McAndrew et al., 2012).

Although the principles of participation are evident in some policy areas worldwide (e.g. Child Family Community Australia and NAPCAN (National Association for Prevention of Child Abuse and Neglect), 2016; Department of Health and NHS England, 2015; Liu et al., 2011; Massey et al., 2012; Nadeau et al., 2012; Tandon and Patel, 2015), WHO recently concluded that participation is not embedded in national strategies (Marston et al., 2016).

Participatory research with young people could play an important role here. Child and youth participation in research is gaining momentum (Gomez and Ryan, 2016; D'Amico et al., 2016; Orłowski et al., 2015; Mason, 2015) and is a valid approach to accessing and representing youth perspectives (Yardley et al., 2015; Prymachuk et al., 2014; Lavis and Hewson, 2011). Participatory research supports meaningful youth involvement, i.e. active engagement and contribution to the research process (Mason, 2015), and is well suited to exploring youth emotional health.

The concept and terminology of participation in research can be applied broadly to an approach, orientation, method, design or methodology aimed at co-production of knowledge between researchers and co-researchers (Bergold and Thomas, 2012). Our study was developed from the principles of participatory research and used participatory methods; for clarity, we use the term 'approach' to refer to both conceptual and operational aspects of the research.

The benefits of participatory approaches were highlighted in a rigorously conducted review of community based, participatory research on child health (Vaughn et al., 2013), which concluded that they directly support the translation of knowledge into interventions development, implementation and evaluation; so this approach is essentially practical. Youth participation in research has produced good quality, applicable, co-produced knowledge in diverse contexts, including: social work priority clarification in Iceland (Fern and Kristinsdóttir, 2011); human immunodeficiency virus interventions in a Canadian community (Flicker et al., 2004); African-American sexual health education (Guse et al., 2013); American-Indian youth services (Langdon et al., 2016); and health service planning with urban Aborigines (Holmes et al., 2002). Participatory approaches enhanced accuracy and truthfulness of results from studies with sick children in an acute care setting (Lambert et al., 2013) and youth with a previous cancer diagnosis (Taylor et al., 2016). The diversity of these studies highlights the need for tailored research designs to suit the context.

Although barriers and facilitators of youth help-seeking for emotional health are well documented, young people's perspectives on how they prioritise their emotional support needs are not well understood; for example, their use of digital mental health resources can be a source of anxiety for carers and health professionals (Eichenberg, 2008; Gould et al., 2003; Kendal et al., 2016). We conducted the participatory research to understand what solutions young people seek to combat barriers to help-seeking for emotional and mental health support, such as cost, access, location, emotional competence and life skills (Plaiستow et al., 2014; Rickwood et al., 2005). Various systems of peer support - for instance, school-based buddy systems to counteract bullying - have been proposed as helpful, though these too can encounter problems relating to the perceived trustworthiness and skill of the young

helpers (Kendal et al., 2013). Given these concerns, it is unsurprising that self-care for emotional health can be a preferred strategy among youth (e.g. Elvey et al., 2013; Martorell-Poveda et al., 2015), an insight which is widely accepted in the literature and was recently endorsed in a comprehensive review (Prymachuk et al., 2014). Thus the research evidence further highlights why youth involvement is important in youth-oriented interventions development.

Three drivers led to the development of this study: public health issues around how best to promote youth emotional health; the principle that support for youth should be informed by youth-led research and solutions development; and the development of a method tailored for meaningful consultation with a specific group of young people.

AIM

The aims of the study were to:

- Develop a participatory method for young people to research their emotional health-related support needs
- Ask young people how these support needs can be met.

METHODS AND OUTPUTS

Our research team consisted of a young person in the 16-18 age group, with expertise in youth emotional health, and three academics with relevant clinical backgrounds (mental health nursing, children's nursing and clinical psychology). Previous research by the authors has explored youth self-care and help-seeking in schools [blinded for peer review], primary care [blinded for peer review] and other community settings [blinded for peer review], so we

had relevant experience and knowledge for this project. We developed a participatory approach in which young people generated and analysed data, in order to prioritise youth perspectives. In presenting the data we have been faithful to the words and phrasing generated at the time, by the young people.

For our study, we developed a consensus method which involved an adapted, nominal group technique consisting of six steps (see Figure 2) – using the focus group method to generate the initial data. The six steps are described below. Consensus methods aid the process of gathering and prioritising youth and adults' perceptions and experiences of health and health care (Tuffry-Wijine et al., 2007; Milnes et al., 2013; Miller et al., 2000). A consensus methods approach was required in the absence of previous literature on the preferences of young people for solutions to problems regarding self-care support. As a consensus method, the nominal group technique facilitates gathering individual perceptions upon which a wider consensus is agreed - a technique used successfully with young people in previous research (Milnes et al., 2013).

Ethics

One of the research team members was under the age of 18. We provided the ethics committee with information supporting her inclusion in the research team on the basis that she was aged 16; familiar with the other members of the research team; able to decide for herself; and had essential insights to support the study. This argument was accepted by the ethics committee. We obtained ethical approval for the study from the University of XXX [name to be inserted] (Ethics Committee 4, ref 13271).

We also obtained ethical approval to include the young people who participated in this study as authors on the present paper. A number of them provided written informed consent to be named as authors and they contributed to writing up the study for publication and are named as authors.

Setting

The study took place in a large city in northern England.

Sampling

Our sampling approach was theoretically informed by Kitzinger (2000) and Mays and Pope (2000). Qualitative sampling aims to produce sufficient data to explore concepts, rather than make statistical generalisations. An homogenous sample can help facilitate reflection on shared experiences; yet depending on the concepts of interest, a small sample of like-minded people may lack representativeness (Mays and Pope, 2000). We aimed for balance, setting narrow inclusion criteria in terms of age (16-18 years), while using flyers and email to advertise locally via personal contacts and networks and in colleges. We gained ethical approval to obtain consent directly from individuals over the age of 16.

We emailed information sheets to individuals who expressed an interest in the study. Those who wished to be involved contacted [first author- name removed for peer review process], who negotiated and then confirmed a venue, date and time using text messaging and email. Participants opted for a teaching room on a university campus that was easily accessible by public transport.

A total of eleven youth participated, of whom ten were in full time education. All had limited availability because of educational, work, family and social commitments. To accommodate this and enhance engagement, we offered two separate focus groups: Session 1 in February 2014 consisted of seven young women; Session 2 in July 2014 consisted of four more young people: two young women and two young men. The sample is described in Table 1. We conceptualised the participants as co-researchers, in view of their active participation in data collection and analysis.

Table 1 Characteristics of the sample

Table 1 about here

Session 1 (February 2014)

We invited the participants (n=7) to lunch before the session started to enable introductions and for the group to become more familiar and comfortable in each other's company. We provided a verbal explanation of the project and obtained written consent from individuals.

Data collection and analysis

Step 1: Using vignettes to facilitate focus group discussions

Participants divided themselves into two small focus groups and [third and fourth authors- names removed for peer review process] facilitated one focus group each. Each group was given vignettes of hypothetical youth with emotional health needs, to stimulate discussion without personal disclosure; plus flip charts, sticky notes and writing materials for recording their discussion. A sample vignette is shown in Figure 1. To reduce the possibility of bias due to the presence of the researchers, facilitators encouraged participants to choose the direction of the discussion. Other than being present to answer questions and provide

support if necessary, facilitators did not participate in the discussions. This activity lasted approximately 50 minutes.

Figure 1: sample vignette

Step 2: Clarifying key issues and identifying solutions

Participants worked together in their small focus groups to clarify their thoughts and identify key issues highlighted from their discussions. Next, all participants came together as a single group. Through discussion facilitated by [fourth author], they produced a list of key issues and then agreed to focus on solutions, resulting in a second list of 11 items (see Table 2).

Table 2: Output from Step 1 and Step 2

The group then reflected on whether any of the 11 items in the second list could be merged. Their discussion generated a shorter list of five potential solutions (see Table 3). This list was written down and displayed on a flip chart.

Step 3 Silent Contemplation

Next, [fourth author] invited each participant to consider the five potential solutions in silence, and give each a score between 1-5; i.e., giving 5 to the most important, 4 to the next most important and so on (see Table 3).

Step 4 Voting

Participants wrote their scores down on sticky notes and placed them next to the appropriate message on the flip chart so that each message on the list had seven scores

attached to it, one from each focus group participant. [Fourth author] added up the scores and then ranked the messages for everyone to see (Table 3).

Step 5: Focused discussion

[Fourth author] then facilitated a focused discussion for the whole group to reflect on the ranking of the top five potential solutions, considering: Why were these items chosen as the top five priorities? What was the group's view of the top scoring key message? Why did they choose this key message? Why did they choose the one with the least score?

Step 6: Revisiting the data

Following discussion, the group repeated the scoring and ranking exercise as described in Steps 3 and 4. There was no change in the scores or ranking (see Table 3).

Table 3: First and second consensus on top 5 potential solutions

Following a whole group discussion about the findings, the participants decided that addressing the top two items could lead to improvements in the other items. Therefore, at the conclusion of Session 1, the young people expressed their agreed priorities as follows (quoted verbatim):

- i. Support [young people] to address their problems
- ii. More recognition of emotional health problems in settings where [young people] are present

The process of data collection and analysis is shown in Table 4.

Table 4: Process of data collection and analysis

Session 2 (n=4) followed the same data collection process but additionally used facilitated discussion to synthesise Session 1 and Session 2 priorities. The outcome was a final list of priorities with overarching themes of Choice and Raising Awareness, representing the combined views of all eleven participants (see Table 5).

Table 5 Ways to support young people (discussion)

Further discussion and reflection by participants of Session 2 brought the study to the conclusion that it would be valuable to have access to a web-based portal to meet many of the information and support needs highlighted from the study overall, and also function as a means to raise awareness of emotional health issues within wider society.

Both sessions recognised a need for a trustworthy resource, e.g. one endorsed by the UK National Health Service and a University. They wanted high quality, easily accessible, confidential, emotional health information and advice. They valued specialists but were open to the idea of consultations with non-specialists, provided they were friendly and had good interpersonal skills.

Reporting

The study was written up by the research team [four authors], and reviewed by the co-researchers named on this paper. This acted as validation for the written interpretation of how the study was conducted and what the findings were.

DISCUSSION

Our study contributes two valuable insights. Firstly, it highlights that help-seeking barriers previously identified in the literature (Gleeson et al., 2002; Plaistow et al., 2014; Rickwood et al., 2005) are relevant to digital emotional health resource development. This is valuable knowledge to support growing international interest in websites and apps for youth emotional health (Sander et al., 2016), which recognises the importance of self-care amongst preventive and protective strategies (Copeland et al., 2014; Prymachuk et al., 2013).

Additionally, the study findings came out of participatory research, which adds validity (Mason, 2015; Orłowski et al., 2015).

Secondly, this research presents an example of a rigorous, participatory approach for learning about young people's emotional health support needs. Guided by previous research such as Orłowski et al (2015) we designed our study for the context and generated insights that are relevant to UK urban 16-18 year olds in full-time education. Since the study findings are consistent with research around youth preferences for emotional health support, i.e. flexible, accessible, trustworthy services and information, delivered or written by friendly, sensitive people in a welcoming environment (Gleeson et al., 2002; Rickwood et al., 2005), we can place our locally relevant study findings within a national and international body of knowledge.

A primary advantage of participatory research is the potential for trustworthy and relevant findings (Lambert et al., 2013; Vaughn et al., 2013). The literature shows that youth participatory research is best achieved where young people can steer all stages of a research project, from planning to evaluation, leading to co-produced, individually tailored designs with more chance of success (Percy-Smith, 2010). We enhanced methodological rigour

through strategies built into the research: the young person in our research team influenced all stages of the study; we tailored the nominal group method to suit our research context, following guidance in the literature (e.g. Fern and Kristinsdóttir, 2011; Holmes et al., 2002); the young people's analysis of their own data and contribution to the writing up process, privileged their perspectives in the final report, as suggested in Lambert et al., (2013); and we conducted the process on two separate occasions, adding an additional level of rigour and analysis to concept development. These strategies are consistent with Mill and Ogilvie (2003), and our findings support Yardley, Morrison, Bradbury and Miller (2015)'s suggestion that participation methodologies generate meaningful and valid research results.

Participatory research can be complex and lengthy, making it inaccessible for small projects (Bergold and Thomas, 2012; Percy-Smith, 2010; Vaughn et al., 2013), but by combining focus groups and nominal group techniques in a single day, we delivered a simple participatory project tailored to our resources of time and access to young people. It accommodated specific considerations when working with young people, to support their full involvement, a voice and collaborative agreement on priorities. We believe it is valuable knowledge that high quality data can be generated from a participatory approach with just two short windows of opportunity.

The principle of children's rights to participate in decisions that affect them has been established for well over 25 years (UNICEF, 1989), yet the perception of youth as social actors and experts in their own experience is still an emerging concept in health research (Murray, 2015). Global and national research and policy highlight youth emotional health as a priority. Issues raised by the study findings suggest a need for better promotion and quality control

of digital tools to support youth emotional health. 'Future in Mind' (Department of Health and NHS England, 2015) is a UK policy document which advocates better use of quality digital resources to support youth self-care for emotional health, but evidence about the impact and quality of such resources is limited (Clarke et al., 2015). Our study articulates young people's reservations regarding trustworthiness and quality. According to what we know about help-seeking, these concerns may limit their utilisation of such resources (Gulliver et al., 2010).

There may be a case for exploring mechanisms for signposting youth to quality-assured digital resources that have been rigorously evaluated by young people. This could relieve some of the safety concerns around their use of the internet to access emotional support (Finkelhor, 2014). Further, the use of participatory approaches to develop a resource could help to nurture a sense of ownership that encourages its uptake.

Strengths and Limitations

Our study demonstrates the feasibility of participatory research in a small project. It was informed by, and contributes to, knowledge about young people's participation in research. The consistency of our findings with the body of evidence around young people's emotional health needs endorses our approach. Consistent with principles outlined in Mill and Ogilvie (2003), each stage of our research was contextualised for the setting to encourage a group of urban youth to engage in the process, from agreeing the dimensions of the issue to validating the findings and reporting. Our approach may be a useful alternative to other participatory strategies such as voting or Delphi studies, which can be limited by low engagement (Wynaden et al., 2014) or a priori assumptions (MacNeela et al., 2010).

The participants were local, with the majority female and in full time education. Hence, they do not represent the wider population of youth in the UK, which is a study limitation.

Nevertheless, the high level of agreement between participants during the data analysis and writing up phases, and the consistency with the literature on YP's emotional health support needs, suggests that both our approach and our conclusions are credible and potentially relevant to other contexts.

Recruitment challenges

Despite proactive recruitment, our sample size was smaller than we had anticipated. Several individuals who said they were interested were not then able to participate, and perhaps more choices of timing could have attracted a wider range of people. The participants provided anecdotal insights about some of the possible reasons for this. A principle one was academic commitments. In the UK, 16-18 year olds in college are likely to be engaged in an intense period of preparation for public exams. As we used personal contacts for recruitment there was a bias in our sample, and we recognise that males and young people out of education were underrepresented.

IMPLICATIONS FOR PRACTICE

Our approach to learning about young people's perspectives appeared to generate trustworthy, credible findings that accurately reflected their views. By thinking creatively and pragmatically, these young people generated a set of principles and solutions that can be translated into interventions development.

The process highlighted young people's interest in emotional health self-care and identified that they may need reassurance of quality and safety when accessing digital tools for

emotional health. This implies a need to explore strategies for establishing the quality and safety of youth-oriented digital emotional health resources.

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Table 1: Participant characteristics

| Participant | Session | Gender | In full time education | College | Recruitment method |
|-------------|---------|--------|------------------------|---------|--------------------|
| 1 | Feb | F | N | N/A | Word of mouth |
| 2 | Feb | F | Y | A | Flyer in college |
| 3 | Feb | F | Y | A | Flyer in college |
| 4 | Feb | F | Y | A | Flyer in college |
| 5 | Feb | F | Y | A | Word of mouth |
| 6 | Feb | F | Y | B | Personal contact |
| 7 | Feb | F | Y | B | Personal contact |
| 8 | July | F | Y | A | Flyer in college |
| 9 | July | M | Y | C | Word of mouth |
| 10 | July | M | Y | C | Personal contact |
| 11 | July | F | Y | C | Word of mouth |

College A: Co-educational
 College B: Girls only
 College C: Co-educational

Table 2: Output from Step 1 and Step 2

| Step 1 Output | Step 2 Output |
|---|--|
| <p>Key issues from focus groups</p> <ul style="list-style-type: none">• Stigma around mental health• Mental health not discussed much in college/school• Negative connotations of counselling• Young people don't know enough about dealing with stress• Not enough study support from colleges• Teachers don't have enough knowledge about mental health• GPs go straight to drugs instead of looking for other solutions• People underreact/overreact | <p>Identified solutions to key issues</p> <ul style="list-style-type: none">• More discussion about removing mental health stigma• Education about mental health from a young age• Counselling in school/college should be more discreet e.g avoid taking people out of class• More info for young people about dealing with stress, e.g., activities, study techniques, pre-sleep routine• More study support from colleges• More about prevention of mental/emotional issues not wait until things are bad• Education for teachers• Sessions for the under 25s in health centres/workplaces/colleges• Advertisements• Find ways to stop people from underreacting/overreacting• Moderated message board |

Notes: Step 1 in this figure presents a list of key issues around emotional health, from the perspectives of the young people. Step 2 represents their own responses to this list, i.e. their ideas about potential solutions to the key issues.

Table 3: First and second consensus on top 5 potential solutions

| Potential solution | First consensus | | Second consensus | |
|---|------------------------|----------------|-------------------------|----------------|
| | Score | Ranking | Score | Ranking |
| Support young people to address their problems | 27 | 1 | 27 | 1 |
| More recognition of emotional health problems in settings where young people are present | 26 | 2 | 26 | 2 |
| Young people need better access to specialists | 22 | 3 | 22 | 3 |
| Professionals could improve their skills at talking with young people about emotional issues | 18 | 4 | 18 | 4 |
| Support for young people could be available in informal settings and/or with non-health professionals | 7 | 5 | 7 | 5 |

Table 4: Process of data collection and analysis

| Step | Activity | Output | Process |
|-------------|--|---|-----------------|
| 1 | Generate data: focus group activity | Key issues from focus groups | Data generation |
| 2 | Clarify issues and identify solutions. Whole group activity. Discussion about potential solutions. Group merges items to form a shorter list of potential solutions. | Long list of 11 potential solutions. Shortlist of 5 potential solutions | Consensus |
| 3 | First vote: individual activity. Facilitator records potential solutions on flip charts and posts on the wall. Participants consider potential solutions in silence and decide on their rank order. | Individual contemplation and perspective | Consensus |
| 4 | Second vote: individual activity Using sticky notes, participants score each potential solution between 1 (least important) and 5 (most important). Facilitator displays scores and totals on flipcharts. | First consensus on top 5 potential solutions | Consensus |
| 5 | Re-visit the data. Whole group activity. Discussion about reasons for choice of ranking. | Data exploring top 5 potential solutions. | Consensus |
| 6 | Reach consensus: individual activity. Repeat ranking activity. Facilitator reviews ranking and confirms with the group. | Second consensus on top 5 potential solutions. | Consensus. |

Table 5: Ways to support young people (discussion)

| Choice | Raising awareness |
|--|--|
| Who, Where, How regarding access | Advertisements: toilets/buses/newspapers |
| Email, phone or online | College tutors |
| Apps with reminders/tracks how well you're doing | College intranets with announcements, contact numbers, links to websites |
| Find ways to practise how to talk about emotional problem | Trustworthiness of information – e.g. university or NHS approved |
| Talking online (e.g. skype without video) - preparation for a face to face appointment | Young minds – partnership Approved by school/college |
| Well-designed website with login section | |

Figure 1: Example of vignettes used in the focus groups.

Lili thinks she has been depressed since she was about 10. She used to think how she felt was normal. She's now 16 and is starting to think she should do something about it but is not sure where to start.

Figure 2

Six-step nominal group process

Step 1: Using vignettes to facilitate focus group discussions

Step 2: Clarifying key issues and identifying solutions

Step 3 Silent Contemplation

Step 4 Voting

Step 5: Focused discussion

Step 6: Revisiting the data