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Project title: Learning from women's experiences: improving our understanding of the physical, psychological and emotional health impacts of domestic violence and abuse (DVA), help-seeking trajectories and outcomes

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Plain language summary

It is estimated that 1 in 4 women experience Domestic Violence and Abuse (DVA) during their lifetime and may approach multiple agencies before they get help. On average women try to leave abusive relationships 7 or 8 times, but may encounter repercussions from their partner and difficulty in disclosing their situation to family members, friends, health care or other professionals. This can lead to extreme social isolation. We aimed to develop a web-based resource which gives real-life accounts of women's experiences of DVA and their outcomes. This may help to increase the options for women in an abusive relationship, suggest ways to improve their self-care, where to seek help and how to make plans to leave.

We conducted in-depth video- and audio-taped interviews with 40 women across the UK, with a range of ages and ethnic backgrounds, who have experienced DVA, asking about the impacts on their physical and mental health, their help-seeking experiences, outcomes and any barriers experienced. The interviews are being used to develop (i) a web-based resource for women experiencing DVA, family members and friends, as part of www.healthtalkonline.org. (ii) a training resource for medical and allied health and social care professionals. Participants were recruited through Patient and Public Involvement groups, advertisements in the media, a dedicated website and specialist third sector agencies. Women were interviewed at a safe location by an experienced female researcher.

We were very careful to ensure participants' safety. Women who felt uncomfortable about videos or audio-recordings being available online are represented by actors, and real names of people and places are deleted.

We found consistent themes in the women's narratives, which have been written up as Topic Summaries for the website. For example, the data provide new insights into the experience of Coercive Control which is now a criminal offence but is poorly understood. We found new insights into the difficulties and dangers faced by women who want to leave an abusive relationship, which counter the often asked question: 'Why didn't you just leave'. We also found that women themselves were so isolated and controlled in the abusive relationship that they generally did not understand that they were experiencing DVA. Our study highlights the need for wide-ranging education into the reality of DVA, which will be part of the dissemination process.

Keywords
Domestic Violence, Domestic Abuse, Women's Narratives, Women's Help-seeking, Women's Health, Qualitative study, Website study.

Summary of research findings

Methods

We recruited a purposive sample of 40 women across the UK who have experienced DVA. They had a range of ages and ethnic backgrounds. Women were recruited via DVA support agencies, patients at GP practices which operate the IRIS model for the identification and referral of women to DVA support agencies, a website set up for our study, twitter and FaceBook.

Women were interviewed in a safe, convenient location using a topic guide that covered all aspects of their experience of DVA. Interviews were video- and/or audio- recorded. Women could chose the form in which clips of their interview will appear on the website, either video, audio, written or spoken by an actor. Three women decided not to have their data included on the website. All participants had the opportunity to check and give approval for the use of their interview data, making deletions if they wished to.

Interviews were transcribed, anonymised and the data were entered into NVIVO software. The research team carried out a thematic analysis which was used as the basis for writing 27 Topic Summaries for the website, illustrated by clips from the interviews. These summaries represent the full range of women’s experiences of DVA, and reflect the most important themes. The topic summaries and associated clips are being processed by the technical team at the DiPEx charity in order for them to appear on the website. All video and audio tapes will be professionally edited.

Some of the participants, DVA professionals and GPs, along with the research team formed an Advisory Panel that met twice during the study, to comment on the process and to advise on the content of the proposed Topic Summaries. They evaluated the material that had been prepared by the research team in June 2016 and, as a result, major changes were made to the format and content of the Topic Summaries, feedback that was valuable in developing the finished product.

Key Findings

We found consistent themes in the women’s narratives, which formed the Topic Summaries for the website. For example, the data provide new insights into the experience of Coercive Control which is now a criminal offence but is poorly understood. We found new insights into the difficulties and dangers faced by women who want to leave an abusive relationship, which counter the often asked question: ‘Why didn’t you just leave’.

Women's narratives confirmed the devastating impacts of DVA on their mental health and also on that of their children, impacts that did not stop when the relationship ended. Specialized therapy may be needed to help women and their families recover from the trauma of DVA, and yet women's accounts reveal a widespread lack of understanding or appropriate support across a range of key professionals in healthcare, the police and children's services including CAFCASS.

We also discovered a number of significant barriers to women in seeking help, which form a Topic on the website entitled ‘Obstacles to seeking help’. Women across all educational levels revealed a lack of knowledge about DVA, so they were not able to understand their partner’s behaviour. Women described being manipulated into believing their partner’s behaviour was their fault and therefore they had no ‘right’ to ask for help.

Other constraints to asking for help included a deep fear amongst women that they might lose custody of their children if their home situation was known about by professionals. Women also said that it was hard for them to open up to anybody about their experiences and urged professionals, family and friends to ask more questions but to be non-judgmental. The very real repercussions in terms of violence from their partner when a woman left was highlighted in the interviews and underlines the need for greater support at this time. For many women, getting a place in a women’s refuge was impossible owing to lack of availability and the need to be eligible for public funding. This was particularly difficult for first generation migrant women.

Our study highlights the need for wide-ranging education into the reality of DVA, which will be part of the dissemination process. Our participants frequently experienced being let down by, for example, the police who had, in the participants’ view, little understanding of DVA beyond physical violence.

Expected impact

The study will be published online as part of the award-winning website www.healthtalkonline.org, a growing resource that specialises in disseminating qualitative studies of experiences of health and illness. The impact of a website is difficult to measure. The site currently covers over 70 health conditions and receives over 5 million hits per month. Following the launch of the DVA module, which is likely to be in March 2017, we will undertake dissemination work to maximise potential impact. We will receive regular bulletins of the number of hits per page from the website charity, so that we can monitor usage over time.

We plan to expand on dissemination and impact measurement following the launch which will include a Press release and media coverage. We are working closely with Women’s Aid to facilitate dissemination. The DVA module will be introduced on the website by some video clips from key informants in the field of DVA. We have made an introductory video of Jenni Murray, Patron of Women’s Aid and presenter of Radio 4 Woman's Hour. Radio 4 has been covering DVA in the last two years through a storyline in the radio series ‘The Archers’ and Women’s Hour has made several reports on the topic. We hope to use this forum to advertise the website module.

We have already taken steps to include findings and video clips in teaching modules for medical students and in academic and non-academic conferences and events. Clips and data from the DVA module will be incorporated in the training for the IRIS model for GPs and other staff in primary care (see www.irisdomesticviolence.org.uk). We hope that the range of topics addressed in the DVA module will strengthen the likelihood that primary health care and other commissioners will commission IRIS and other DVA resources. Small cards and/or posters giving the web address of the DVA module will be available to be distributed to interested parties, for example GP practices, hospitals, police stations, DVA agencies, other public places. Attempts till be made to disseminate into other professional areas such as the training of police or the education of young people. One potential method for doing this is to create a piece of ‘verbatim theatre’ in which actors speak the words of women survivors of DVA, taken from their narratives, and developed into a piece of theatre. We plan to apply for funding for dissemination and impact assessment work.

The balance of the grant (under £4,000) will be retained for 12 calendar months so that we can undertake planned dissemination work, which will include professionals' study and information days and attending international conferences about DVA (please see spreadsheet for details).

Conclusions

A resource such as the www.healthtalk.org module about DVA could be used in a variety of health care, social care and educational settings, to increase public and professional understanding of DVA. Most of the women said that, had they known about DVA in all its various forms, they might not have stayed so long in an abusive relationship, and they would have sought help earlier.

A positive outcome was the number of women who experienced support from other survivors of DVA. For many women, simply talking to someone else who understood, was the beginning of their own journey away from abuse. Providing and evaluating information, resources and training to facilitate women in setting up and advertising peer support groups could be valuable future research proposals.

Patient and public involvement

Working with our PPI group of women survivors of DVA has been essential to the success of the study. I feel strongly that PPI representation should not be tokenistic, such as one or two PPI members on a steering group that mainly comprises academics and other professionals, which will enable only the more confident or articulate to participate. I also resist the move towards the 'semi-professionalisation' of PPI members that I see in evidence around me, whereby individuals with a particular illness condition are recruited because of current or past professional skills that are relevant to the research rather than for their personal experience of the condition that is being studied. I have witnessed formal application forms and interviews for PPI positions, which I wholly disagree with. Our role as professionals is to objectify the condition under study and as far as PPI members are concerned it is important to prioritise their subjective experiences, not their confidence or articulate-ness or professional skills.

With this in mind, we recruited a group of women survivors, some of whom had worked with us on previous studies, and who met regularly during the lifetime of the study. Meetings were held at the University, pre-paid taxis were booked to enable women to attend, lunch was provided and shopping vouchers of £20 were provided in appreciation of their time and contribution. Four members of this group volunteered to join the project Advisory Panel that also included professionals from Women's Aid, the local DVA agency, the IRIS programme, GPs with expertise in DVA and the core research team.

PPI members were involved in developing the funding application, helping to prioritise the research aims and develop the methodology. They provided important insights into issues of confidentiality and safety in terms of recruitment, data collection and use of the data on the website. When funding was secured, PPI members assisted in the development of participant information resources, commenting on the design and wording of all research documents such as participant information sheets, consent forms and topic guides. We agreed to implement a safety button on each page that instantly closes the website down should a woman be disurbed while One innovation that arose from this process was the design and use of a coloured flyer which was widely disseminated. It showed a woman's face with speech bubbles asking key questions to identify DVA. This was used as the initial stage of recruitment, before the full information sheets were provided. Another example was the agreement to include a safety button on each page that quickly closes the website down if a woman is disturbed while accessing the site.

We held two Advisory Panel meetings during the lifetime of the study, which were lengthy working sessions. All members were sent data in advance and invited to comment. At the second of the two meetings, we drafted the Topic Summaries for the website and we had a very lively meeting following which I changed the focus of the data analysis in line with the feedback from the survivors. Drawing on their own experience they were able to steer the way in which the data was analysed, so that we reduced the emphasis on some topics and expanded others. One example of this is the use of a large amount of data in the interviews relating to the effects of DVA on children, some very long-term, and women's struggles to get help and support for their children. We had not originally processed this data as it seemed to take the focus off the women and we also feel that we have enough data on children to potentially write another healthtalk module! However, all the women felt that impact on children was one of their prime concerns. When we analysed the data we realised that the impact on children was both a reason for women to stay in an abusive relationship and also a reason for women to get away. Although the analysis and processing of this data provided a lot of extra work, we feel that the module is better as a result. Our panel representative from the HERG unit at Oxford (which leads the research for the website) commented that it was one of the best, well attended and inclusive meetings she had attended.

The PPI women continue to be involved, some have offered to proof-read the material for the website, others are personally attending conferences and meetings to speak about their experiences of DVA and their experiences as research advisors. When the module is ready, we will involve PPI women in a short evaluation and checking, followed by the launch. We will continue to consult and involve the women in our dissemination plans.

Data sharing statement
See link [https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to

patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

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This project was carried out between September 2014 and November 2016 . This final report has not been peer-reviewed. The report was examined by the Programme Director at the time of submission to assess completeness against the stated aims.