Public involvement in designing a study on patient-witnessed cardiopulmonary resuscitation in hospital

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ABSTRACT

AIMS AND OBJECTIVES

The aim of this paper is to report the findings of the consultation rounds with former patients and healthcare professionals to inform the design of a qualitative study. We aimed to understand stakeholders' views regarding the relevance of a proposed study looking at the impact of patients witnessing cardiopulmonary resuscitation on other patients in hospital, the appropriateness of the proposed methodology and ethical aspects.

KEY ISSUES

We conducted an online survey (n=22) and telephone interviews (n=4) with former patients linked to the British Heart Foundation charity and a focus group (n=15) with hospital healthcare professionals involved in resuscitation activities. Data were analysed through thematic analysis. The consultation rounds provided valuable advice on three major themes: conceptual aspects, methodological aspects and practical suggestions. The conceptual aspects were related to the relevance of the proposed study, the emotional impact for participating patients, and how the social interaction among patients could influence the witnessing experience. Methodological advice related to recruitment strategies and data collection methods such as the use of individual and focus group interviews, the timeframe of interviews with patients, and the topics of the interview guides. In the third theme, practical suggestions were provided, such as strategies to advertise the study, improving the

public and participants engagement throughout the study process and disseminating the findings. Overall, the study proposed in this consultation was considered relevant and worthy by patients and healthcare professionals to raise awareness and generate new evidence on an unconsidered aspect of resuscitation and of patients' hospital experience.

POINTS OF LEARNING FOR CRITICAL CARE PRACTITIONERS

These stakeholders' consultation rounds constituted a valuable exercise to design high-quality research based on a shared vision among researchers, service users and clinicians. They also provided pragmatic advice to inform critical care practice to support patients witnessing cardiopulmonary resuscitation in hospital.

BACKGROUND

Witnessed cardiopulmonary resuscitation (CPR) is a research topic that is gaining attention in the last decades. In the UK, the average incidence of in-hospital cardiac arrest is around 1.1 per 1000 hospital admissions, (National Cardiac Arrest Audit, 2018). While a considerable amount of literature regarding family-witnessed CPR has been published (Toronto and LaRocco, 2019, Breach, 2018) and guidelines for supporting family members have been established (Fulbrook et al., 2007), evidence investigating the impact of witnessing CPR of other patients in hospital and addressing the support they may need is still limited (Fiori et al., 2017). The need to extend the knowledge on the framework of witnessed CPR in further directions has been highlighted in the nursing research agenda, including the perspectives of hospital patients who witness CPR of other patients and of healthcare professionals involved in their care (Köberich, 2018, Walker, 2006).

The involvement of the public and patients (PPI) is becoming an integral part of health research (Brett et al., 2014). There is an internationally growing interest in involving patients and the public to set new research priorities that respond to stakeholders' needs and concerns in healthcare (Dent and Pahor, 2015, Frank et al., 2015, National Health Medical Research Council, 2016, McKenzie et al., 2017, Canadian Institute of Health Research, 2018). In the UK, the organisation "INVOLVE", established in 1996 by the National Institute of Health Research (NIHR), advocates the co-production of research projects supporting active cooperation between the public, practitioners and researchers (Hickey et al., 2018). In addition, most research projects in the National Health Service (NHS) are reviewed for ethical approval by a Research Ethics Committee (REC). Therefore, robust PPI consultations represent an essential part of the ethical review application, describing the role of the public and

patients in designing and delivering the research (INVOLVE, 2016). In particular, at the very early stage of developing a research protocol a PPI consultation is highly valuable to address patient-relevant outcomes (NIHR, 2014).

A well-established tradition of public engagement involves mostly disease-specific and long-term condition patient groups. The long-term relationship between users and health services often facilitates the level of trust and mutual engagement and the specific disease allows identifying a clearly defined population (Hirst et al., 2016). However, when conducting research in emergency or critical care, involving the public and patients might represent a challenge (Burns et al., 2018). Emergency care is characterized by short term, broad range of application and heterogeneity of patients (Hirst et al., 2016). CPR is, by definition, an emergency life-saving procedure, which every person could potentially be exposed to. It does not refer to disease-specific patient population and it may be encountered in different settings. Therefore, researchers may face challenges in identifying patients to involve in research at the design stage and beyond.

Despite the joint effort of professional and public organisations in setting research priorities in emergency care (Smith et al., 2017), the views of stakeholders regarding patient-witnessed CPR in hospital are yet to be explored. Therefore, in line with NIHR guidance for researchers (NIHR, 2014), the views of multiple stakeholders were sought on the design of a proposed research study exploring patients' and healthcare professionals' experiences of witnessing CPR of other patients in hospital.

AIM

The aim of this paper is to report the findings of PPI consultations with people with heart diseases and hospital professionals involved in CPR activities to inform a study proposal on patient-witnessed CPR in hospital. The objectives of the consultation were to determine their views regarding:

- The relevance of the research question and the aim of the proposed study;
- The appropriateness of the proposed design and methods;
- The ethical feasibility of the proposed study.

METHODS

Approach

An exploratory inductive approach with qualitative methods was used to understand the stakeholders' opinions on the proposed research study, which is summarised in Figure 1. A qualitative online survey and semi-structured telephone interviews were conducted among people with heart diseases. A focus group was conducted with hospital professionals involved in CPR in a large acute hospital. The consultations were conducted between February and June 2017.

In line with the NIHR and INVOLVE statement on ethics and PPI exercises, formal ethical approval was not required to conduct these consultations since the involved people were acting as specialist advisors in planning and designing a research protocol (NIHR, 2014). However, ethical measures to protect confidentiality and data protection, such as anonymization and secure data storage were undertaken, following the Good Clinical Practice

(GCP) and qualitative research ethics guidelines (European Medicines Agency, 2017, Richards and Schwartz, 2002).

Public and professional involvement and recruitment

Members of the British Heart Foundation, a UK based charity supporting people with heart diseases, were involved in these consultations. The charity allows researchers to access its patients' involvement network *Heart Voices,* which includes volunteers interested in taking part in research consultations. The *Heart Voices* Patient Engagement Officer helped the researchers to e-mail to the volunteers a plain English summary of the proposed study, the consultation purpose and a link to participate in an online survey. In literature, a sample size ranging from 15 to 50 participants is considered adequate for a small project based on qualitative surveys (Braun and Clarke, 2013). For this exercise, a sample of 20 advisors was considered large enough to gain sufficiently rich feedback. The advisors were people with heart disease who had been hospitalised and who were willing to share their experience. Responders who agreed to be engaged further in the consultation process, by replying directly to the researchers' e-mail, were contacted to arrange a follow-up telephone interview.

Fifteen professional stakeholders were invited to participate in the consultation during a study day for professionals involved in CPR and representatives of different hospital wards. In agreement with the resuscitation officers, the outline of the study was presented during the Resuscitation Link Nurse/Person meeting, held at the hospital site, which involved registered nurses and other health professionals. Prior to the meeting, a study summary was e-mailed to the participants, explaining the purpose of the consultation. At the meeting, the

researchers presented the outline of the proposed study and invited the healthcare professionals to share their views in a focus group.

Data Collection

Volunteers of *Heart Voices* participated in an online survey and subsequent telephone semi-structured interviews. The research team developed the online survey using SurveyMonkey and published it online. The survey included six open questions regarding the relevance of the research topic and the proposed study design. The *Heart Voices* Patient Engagement Officer reviewed the draft of the survey for suitability prior to forwarding it to the members. The web link to the online survey was available for a duration of four weeks.

Subsequently, telephone interviews were used to get a deeper insight of the stakeholders' views on some of the themes raised in the survey. A semi-structured interview guide was developed based on the preliminary analysis of the survey responses. The interviews were audio-recorded and transcribed. After the transcription, the audio records were destroyed and the transcripts were anonymised.

The consultation with the professional stakeholders was completed as one focus group. The research team developed a semi-structured discussion guide focused on feasibility and logistical considerations, as participant recruitment and data collection methods. In agreement with the professionals attending the focus group, the discussion was not audio recorded. A second observer made detailed notes of the discussion without adding any personal details of the participants nor reporting any direct quote.

In total, 37 stakeholders were involved in these consultations. Twenty-two members of *Heart Voices* participated in the online survey; of these, three men and one woman (n=4)

voluntarily contacted the researchers after the survey to be further involved in the consultation and took part in one telephone interview. Telephone interviews lasted from 14 to 50 minutes. Fifteen healthcare professionals took part in one focus group interview. The focus group comprised twelve registered nurses, one radiographer, one matron and one resuscitation officer and lasted around one hour.

Data Analysis

The data generated from the qualitative survey, the telephone interviews and the focus group were organised using NVivo 11. Data were analysed through thematic analysis (Braun and Clarke, 2006), using an inductive approach, not driven by any existing theory to allow frequent and significant themes to emerge from the data. The first author (XX) read and re-read the full transcribed text for familiarisation with the data and formulated an initial index of codes. Similar codes were merged together in sub-themes. The sub-themes were then renamed and collated together under potential main themes. Two experienced researchers (XX and XX) reviewed the identified themes and sub-themes. Data collected from the consultations were analysed separately for each stakeholder group and subsequently merged together under three final themes: conceptual aspects, methodological aspects and practical suggestions, summarised in Table 1. Rigour and trustworthiness were ensured through participants' checking of the telephone interviews and focus group transcriptions and through the review of data collection, analysis and interpretation of findings process by the research team members (XX, XX, XX).

FINDINGS

Conceptual aspects

Overall, all the stakeholders considered the study very relevant to allow the researchers to gain new knowledge about patient-witnessed CPR, to give voice to the witnessing patients and to shed a light on the current practice in hospital wards. In fact, professional stakeholders emphasised during the discussion that although resuscitation officers and nurses do informal checks on patients witnessing CPR answering their questions, this is not a standardised practice everywhere and needs further exploration.

A main theme arising from the consultation was the emotional impact that witnessing resuscitation can generate on patients. Witnessing CPR was considered by many stakeholders potentially traumatic and the lack of privacy was one of the factors potentially influencing the experience:

> *"But if you are in a bay, let's say six beds, and something happens to one of the other people in that bay, all the other five people are always involved as well, aren't they? They have all been affected."* [Ref.1, telephone interview]

The need to share the experience with somebody appeared to be important, too. This aspect was linked to the importance of providing emotional support after the event and follow-up with patients on possible long-term consequences of the experience:

> *"I think it is very important to support somebody because I've spoken to many people that witnessed a cardiac arrest, and they need to speak about it, because otherwise if they keep it for themselves it is going to affect them quite badly."* [Ref.4 telephone interview]

Another important theme regarded the social interaction between the patients, and its impact on the witnessing experience. Elements such as the length of the hospitalisation, the medical condition, the bond developed between the resuscitated patient and the witnesses, and mechanisms of social comparison seemed to have a role in determining the whole experience:

> *"The degree of friendship they had developed with the person receiving CPR is also important. At one of the events that I witnessed, a fellow patient was shouting and trying to get to the bed as she felt she could help her 'friend' and they should not give up on her. I think this is different to seeing someone coming in via A&E or with whom you had never talked to or shared a bay."* [Ref. 1, telephone interview]

> *"I knew that happened, I knew it was shocking and I also knew the patient passed away […] and it actually caused some concern to me, because I thought – Is it going to happen to me?-"* [Ref.3, telephone interview]

Methodological aspects

Both consultees groups discussed recruitment strategies to involve in the study patients who witnessed CPR. A general consensus was reached on early recruitment within the first few days after the event, while some concerns regarded the modalities of recruitment and the professional figures involved. Most stakeholders agreed on allowing some time between the recruitment and the interview to let the participants reflect and prepare themselves for the conversation. Professional stakeholders suggested involving the resuscitation team to flag up

the CPR events to the research team during daytime and engaging the ward nurses to promote the study with eligible patients.

BHF consultees considered face-to-face interviews an appropriate data collection method to explore patients' experiences deeply:

> "*I think face-to-face interviews are essential for the first interview […]. Witnessing such an event is very traumatic for other patients, and I think a personal interview should be conducted privately. I think the interviewer should be prepared to spend a long time with some interviewees so that they can relive the experience and cope with the questions.*" [Ref.2, online survey]

They also provided relevant suggestions on how to develop the interview guide including how to introduce the study:

> *"I think you need to put the patient at some sort of ease and explain them the protocol."* [Ref 3, telephone interview]

Prompting initial specific questions to understand the context and break the ice:

> *"I would like to start with this sort of specific* (questions) *to get into it for example: what time of the day did it occur? Did they know the patient well? Who actually carried it* (CPR) *out? […] they are kind of specific* (questions) *and easier for them to answer initially."* [Ref.1, telephone interview]

And final open questions about the experience of witnessing CPR and the developed feelings:

"*I wouldn't put more specific things on things like ehm…-can you tell me how you felt about it? What thoughts did you have?- I think those just need to be left totally open for them to say their views."* [Ref 1, telephone interview]

Everyone agreed with the need of a private space to conduct the interview in hospital. Consultees of both groups suggested allowing the presence of a third person during the interview, as a relative, to reassure the patient and provide an independent perspective of the experience.

Professional consultees considered focus group interviews a valid method to explore healthcare professionals' experience on supporting patients witnessing CPR. However, some concerns arose regarding the logistical organisation of the interviews, considering the workload of the hospital staff and the difficulties in gathering groups of participants at once. Therefore, consulted professionals suggested conducting individual interviews besides focus groups, with professionals who satisfy recruitment criteria to accommodate to their schedule and increase the chance of participation.

Practical suggestions

Stakeholders highlighted a number of suggestions considered valuable by the researchers. Patients stressed the need to seek also professionals' perspectives and the emotional impact on professionals and family members:

"*The staff need to be interviewed about their feelings too and why they are resistant to discussing the incident with the other patients. It's a bit like an elephant in the room…we all see it happening then nobody talks about it.*" [Ref.8, online survey]

This is also reflected in the discussions with the healthcare professionals: a member of the group reported that in some areas the staff take few minutes to debrief about the event. They reflect on what happened, what went well and what did not and what kind of support can be provided to the rest of the staff involved and the patients.

BHF consultees stressed the point of keeping the public involved during all the research. Considering medical team advice in identifying suitable participants and acknowledging the context of the event, the conditions and the possible emotional burden of the witnessing patients was also recommended:

> "*[…]All people are individual and unique, and all feel, think and act differently. When compiling a study, every single difference has to be factored in. […]*" [Ref.6, online survey]

They also suggested the researchers to approach patients together with a staff nurse or a member of the CPR team, to help establish a trustworthy rapport. Some professional stakeholders suggested advertising the study in the hospital through fliers, internal communications, presentations to senior staff meetings to facilitate the participation of healthcare professionals in the study and their engagement in patients' recruitment. Others proposed to introduce the discussion of the study during daily debriefs in the wards. Both groups of consultees stressed the importance of disseminating findings among relevant audiences. Patients suggested spreading the results through the BHF newsletter and public events, while professional stakeholders proposed presenting the results during study days for staff in the hospital.

DISCUSSION

This paper appears to be the first published work presenting stakeholders' consultations on the perspectives of patients and professionals on patient-witnessed resuscitation. This exercise makes a valuable contribution to the design and the development of a research study aiming at exploring the impact of patient-witnessed resuscitation from patients', nurses' and other healthcare professionals' perspective (Fiori et al., 2019).

The findings of this consultation showed that all participating stakeholders considered new research on patients witnessing resuscitation highly relevant and necessary. Findings highlight that resuscitation involves everyone in the room. Witnessing patients might find the experience distressing and there seems to be a need among patients to improve disclosure about the incident.

The four consultees who participated in the telephone interviews reported that in their previous experiences of witnessing CPR, they might have found beneficial to discuss the incident with healthcare staff. Similarly, the need to disclose with a member of staff when patients witness the deterioration of fellow patients was found in a study exploring patients' interaction in a hospital ward. (Laursen, 2016). In both cases, patients' need for support was not always met by healthcare staff. Patients often engage with other patients and share their feelings and concerns among them. Peer support during hospitalisation appears to provide a unique sense of empowerment as patients feel understood by a peer that has been through a similar process (Borregaard and Ludvigsen, 2018), but this cannot substitute for professional support.

These consultations provided valuable information on methodological aspects too. Patients were mindful of the impact of CPR on healthcare professionals, supporting the inclusion of hospital staff in the study population. Perspectives and practices of healthcare professionals have been previously investigated mainly regarding family presence during resuscitation (Sak-Dankosky et al., 2014), but not toward witnessing patients yet. To facilitate participation, consultees suggested adopting multiple data collection methods, as individual and focus group interview. The use of multiple data collection methods is supported to help triangulation (Patton, 2002) and in nursing research the combination of individual and focus group interviews is adopted to enhance data richness (Lambert and Loiselle, 2008). Consultees also advised on recruitment strategies, supporting early patient recruitment, but allowing a flexible interview time schedule.

Within the scope of designing a research study, these findings raise ethical reflections about researching on sensitive topics. Nursing and health research often focuses on aspects of life that are considered sensitive (Enosh and Buchbinder, 2005), but although facing some ethical challenges, exploring these topics is essential to gain a deeper understanding of patients' needs and to progress towards better care. Consultees suggested including support strategies to help patients coping with the potential discomfort of the event and of the interview. Therefore, on-site support services were involved to ensure that study participants would receive appropriate information and practical advice about possible emotional responses they may encounter. A supportive approach was maintained from the development of the guide until the conclusion of the interview. Interview guides were based on consultees' advice of asking open not leading questions and limiting closed questions to set the context of the event. Additionally, other strategies of sensitive questioning supported

by the literature were adopted (Nieswiadomy, 1998, Cowles, 1988, Elmir et al., 2011). A certain flexibility in the interview guide was allowed to let the topics emerge gradually following participants' pace (Brannen, 1988).

Finally, following stakeholders' advice of keeping the public engaged during the whole research process, the BHF consultees involved through the telephone interviews were invited to constitute an advisory group to consult with the research team throughout the further stages of the research.

Limitations

We are aware that these stakeholder consultations have some limitations. The recruitment of a very specific sample may not reflect the full spectrum of views of patients and healthcare professionals towards the proposed study. People with heart disease involved in the consultations were recruited through *Heart Voice,* therefore keen to participate in research consultations. In the same way, participating professionals were all involved in CPR activities in the hospital, either in first line or as spokespersons of the resuscitation team in the different wards. Therefore, their views and overall support for the proposed research might not reflect the views of the clinical hospital staff who do not deal often with CPR.

CONCLUSION

This consultation provided valid feedback on the relevance and feasibility of a research study on patient-witnessed CPR. The findings enhanced conceptual, methodological and ethical choices taken in the development of the study protocol and highlighted research points that need to be addressed. The enthusiastic participation of stakeholders in our consultations encourages the advancement of health research in partnership with the public, patient and

professional stakeholders. These consultation rounds have been informative and significant to perform high quality research on the impact of patient-witnessed CPR in hospital and to address future clinical practice in critical care.

IMPACT

a) what is known about the subject

- Witnessing CPR may represent a stressful experience that has been investigated from different bystanders' point of view, but not from fellow patients' perspective.
- Involving public, patient and professional stakeholders in defining research priorities is now paramount to design and deliver sound healthcare research responding to user and professional needs.
- The views of stakeholders on research focusing on patient-witnessed CPR have not previously been explored.

b) what this paper contributes

- This paper outlines an overview of multiple stakeholder opinions on the relevance of a novel research study on patient-witnessed CPR and provides methodological advice on conducting the proposed study taking into account participant needs.
- It gives an insight on the main ethical issues identified by former patients and healthcare professionals.
- Finally, it provides a worked example of strategies used to conduct a successful PPI consultation.

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Figure Legends

Figure 1 Summary of the proposed study

Table 1 Findings of the consultation rounds

Figure 1 Summary of the proposed study

The WATCH study: Witnessing an ATtempt of CPR in Hospital

Our study proposal:
Impact and support of hospital patients witnessing a resuscitation attempt on other patients: a qualitative study.

Why we need to do our study?
Cardiopulmonary resuscitation (CPR) involves receiving chest compressions and/or defibrillation. This lifesaving procedure is carried out when someone stops breathing or has no heartbeat. Every year in the UK thousands of hospitalised patients witness CPR carried out on other patients. At present, little is known about the impact of patients who witness a CPR on other patients.

What we aim to do?
We aim to investigate the impact of patients who have witnessed CPR on another patient and to identify the best support that can be delivered to patients by healthcare professionals. Therefore, our objectives are to:
- Explore the experiences of hospital patients after witnessing CPR on another patient;
- Identify the experiences of healthcare professionals involved in CPR and the support they provide to their patients;
- Define barriers, enablers and best practices improving the support to in-hospital patients who witness CPR on another patient.

How we plan this study?
We will conduct semi-structured interviews with 12-15 patients and four focus groups with 4-8 healthcare professionals to explore their experiences.
Patients willing to participate must have had an experience of witnessing CPR on another patient. Two interviews per patient will be done. The first interview, while the patient is still in the hospital, aims to explore the initial impact of witnessing CPR. The second interview will take place after four weeks and aims to explore the longer-term impact of the experience.
For the healthcare professionals, the focus groups will explore the experiences, attitudes and views of providing support towards patients who witness CPR. Only healthcare professionals who have had a recent experience of a CPR event on their ward will be invited.

What we hope this study benefits?
With the findings of the study we will develop and implement practice guidelines to support patients who witnessed a CPR event. These practice guidelines will help patients to cope with their stressful experience. Above all, we will share our new knowledge with colleagues, patients and the public to provide better care to our patients.

Table 1. Findings of the consultation rounds

Themes	*Sub-themes*	*Codes*
Conceptual aspects	Relevance of the study	Awareness on the other patients' perspectives
		Current practice in hospital
		Beneficial value
	Emotional impact	Potentially traumatic experience
		Lack of privacy
		Need of sharing the experience
		Need of support
	Social interaction	Patients' relationship
		Patients' conditions
		Length of hospitalisation
		Social comparison
Methodological aspects	Patient Recruitment	Early recruitment
		Involvement of resuscitation team
		Follow clinical team advice
	Patient data collection	Face-to-face interviews
		Open questions
		Flexible time schedule
		Presence of a third person
	Professionals data collection	Focus group
		Individual interviews
		Logistic Organisation
		Separate for resuscitation team
Practical suggestions	Seek professional and family perspectives and emotional impact	
	Acknowledge patients' conditions, context emotional burden	
	Keep the public involved	
	Advertise the study to increase visibility	