

Reflections and Projections: Service User Involvement in Palliative Care Research

**Disability Studies: Putting Theory Into Practice.
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Introduction

The 'Influencing Palliative Care Project' is a collaborative research project in which a group of service users with first hand experience of life limiting conditions have joined forces with a researcher to work together on the project.

It is considered that joining together like this to carry out research fits with the ethos of palliative care (explored a little more below) and that this joint working will benefit the research. This research is still ongoing and we will be better able to discuss this when we all have time to look back over the research and our time working together.

This short overview begins by describing the research we are undertaking and then goes on to describe the Research User Advisory Group, which consists of the service users and researcher working on the project, and the process of joint working.

The three people named at the top of this writing all contributed to this paper and Di and Mandy are the conference presenters.

The Research

Beginnings and evolution

The research began as an idea of Phil's who at that time was working with people with advanced cancer as a hospice community nurse. He was interested in the difficulty people who are very ill have in getting their ideas and wishes across. He was also concerned about the lack of service provision for people with other life limiting conditions.

Key people locally were contacted to discuss the initial ideas and it was Di who suggested bringing together local service user groups in the area to discuss these concerns and to establish if they shared these same concerns. They did, and the Research User Advisory Group evolved from this initial meeting.

We are now at the data interpretation stage of the research.

Research questions

The main research questions focused upon what help or assistance service users with life limiting conditions needed from health and social care services and what was actually received. It also included the way people were treated by others; the experience of living with their condition, and what level of choice and say they had with regard their own situation.

Why a participatory/emancipatory approach to the research?

A collaborative approach to research was considered to fit with the basic principles of palliation, which include honesty and truth telling, discussion of choices/options and autonomy, a whole person approach to care, and effective communication.

Palliative care and inclusion

Despite this, certain exclusions exist within palliative care;

service provision tends to neglect people with non-malignant conditions (i.e. heart failure, chronic lung diseases and HIV+/AIDS); people from black and minority ethnic communities are less likely to access palliative care services; palliative care organisations can be hierarchical and inflexible in structure.

Participants – who are they?

Twenty-five people have been included in the research. Slightly more women than men; 14 people with cancer and 11 with other conditions (i.e. COPD, HIV+, ME, MS, Sub-arachnoid haemorrhage); age range 38-85 years. 10 people have died since their involvement in the research.

Some initial findings:

a) Experience of services

A real difference is being seen between people who have a cancer diagnosis and can access palliative care via a hospice and those with non-cancer conditions who are not able to access the hospice. People with cancer experience hospice services very positively after initial fears.

They value meeting with others in a hospice day centre, having access to specialist staff, and feel assured that their families and friends will be cared for when they become less well and after death.

People who have non-cancer conditions often report problems with their condition being diagnosed, in their relationships with professionals and in gaining the level of service they feel is needed.

Home care and social services are often highlighted as lacking in certain aspects (i.e. timing of visits, changes in staff, and staff attitudes).

b) Impact of diagnosis and impairment

The clear impression gained here so far is of people's lives being turned upside down, of diagnosis as a traumatic period with the after effects being a total change in how life is lived. People told us of their growing isolation as friends fall away and as impairments restrict them. People also told us of their exhaustion and frustration.

c) Relationship changes

People were grateful for family members who stood by them but there were many examples illustrating how some friends have drifted away and how some people find themselves getting ostracised. People told us about being misunderstood by people and how difficult it is explaining yourself over and over again.

Differences and similarities

There are stark differences between people's experience of their condition depending upon the type of condition they have. People with cancer describe satisfaction with services provided by hospices but people with non-cancer conditions who were unable to access this service were often unhappy with many services they received.

Regardless of the type of condition, people spoke of many similar issues that were causing them problems, such as physical problems caused by their conditions, challenges to certain relationships, not being listened to and respected as much as they would like, and a sense of abandonment by friends and services.

Research User Advisory Group

Aims and Terms of Reference

The Research User Advisory Group aims to ensure that the research stays in tune with service user concerns and needs and aims to enable group members to influence the research at all stages of the research process. Group members will have influence on the outcomes of the research i.e. in terms of action or change supported by the findings of the research.

The group operates in line with clear terms of reference.

Who are we?

Between five and eight people have made up the group over the last 18 months and people with a variety of conditions are members. Because of the nature of the group some members have died.

What do we do?

The group have worked on the interview questions asked; given input into the way interviews have been conducted;

contributed to data interpretation and the general monitoring and progress of the research. Group members have also been involved in a range of teaching opportunities about the research and how we are doing it.

As a result of people's involvement in the group and their work on this research, opportunities have also arisen for members to teach in other settings as well and to get involved in other initiatives separate to this research.

Research and Involvement's effect on us

Group members have found involvement in the research to be challenging at times but overall have found the experience to be empowering and worthwhile. At first, service user members were uncertain and lacked some confidence. However this confidence has grown over time and everyone has helped each other. Some of the information from research participants has been 'close to home' for service user group members, bringing up very familiar issues and prejudices.

Research Process

Service user impact upon the research

Service users have kept the research focused on the concerns that they share with participants and have added an interesting commentary on the data generated from interviews. They have shared some of their own experiences of living with life limiting conditions when it is relevant to the research. This has helped to keep the researcher focused upon the issues that arise from the research and from service users concerned rather than directing attention elsewhere.

Working together – what has it been like?

We evaluated the way we have worked together on this research and highlighted some areas that would be helpful to improve. The way the group meetings are conducted has needed to adapt over time; group members want to be more involved in the research and some have now become honorary researchers with the hospital trust in order to get more involved;

the research is often seen as 'Phil's research' although group members have a strong desire to see it through and for it to lead to changes for service users. They see it as future orientated and are hopeful of positive developments to come as a result of the research.

One unexpected outcome from the research and the Research User Advisory Group has been Mandy and Di's determination to establish a service user/carer group for people with all life-limiting conditions with the dual aims of support and lobbying.

Insights and thoughts – researcher/service users

Researcher- Phil can't imagine doing this research without service users direct involvement in it. Service user involvement in the advisory group has made the research more meaningful and the passion for change and for being heard that they have, has been very motivating. Gaining group members insights about the data collected has offered a form of data validation. The process of data interpretation we are still doing now is extremely valuable.

Service users/group members-Group members speak of many personal benefits to being involved with the

research i.e. increased self-esteem, sense of purpose,
feeling of camaraderie and friendship,

sense of participating in something worthwhile and in something that will improve services and care for people with life limiting conditions.

What do we want to happen with the research?

The Research User Advisory Group is determined to disseminate the research to local service providers so that appropriate changes may result from this research. This may take the form of service and attitude changes. We want people in positions of influence to listen to what we have found in this research. We also want to speak with a wide range of service user groups in order to promote discussion and action on issues that arise from the research.

What might be the lessons to learn?

There are two main areas:

1. Service users who have life limiting conditions can work effectively on research projects, make a significant contribution, and should be offered the opportunity to do so.

2. The research itself is still being analysed but it is clear that people are treated very differently dependant on diagnosis rather than need, and this needs to be challenged.

Services need to be more focused on individual need rather than a 'one size fits all' type of attitude. There is much room for staff training about service user needs and attitudes towards service users require some improvement.

Would we get involved in this sort of project again?

All group members would be interested in other projects so long as the research has the possibility of leading to improvements for service users.

Despite extreme difficulties in actually getting to Lancaster to present this paper both Mandy and Di wanted to come to prove that people with life limiting conditions are not to be written off.

The Social Model of Disability in relation to this project

Static and progressive conditions

With most life-limiting conditions impairment is ‘in your face’, almost impossible to ignore, ever changing and, most probably, deteriorating. This may be challenging to the social model of disability in that these impairments are often at the foreground of peoples desire for change and occupy a great deal of peoples attention.

Social manifestations of disability also exist for people with life limiting conditions but may be more difficult to see and to challenge.

From too ill to talk to ill and involved?

Caution about service user involvement in practice and research within palliative care has been commonplace with many people suggesting that people with life limiting conditions may be ‘too ill to talk’ (i.e. Small and Rhodes, 2000). Other recent experience, including this research, highlights the fact that a collaborative research approach can not only be possible, but can bring very positive

outcomes in terms of personal benefits for service users and in terms of useful and credible research findings.

The Research User Advisory Group sees the importance for service users getting involved in a range of initiatives.

People with life limiting conditions, impairments and disability

Impairment barriers are obvious but there may also be other subtle, social and cultural barriers in place that exclude people with life limiting conditions from their place in society. For people with non-cancer life-limiting conditions there is discrimination within health and social care that regards and treats them in lesser ways than if they had a diagnosis of cancer. This 'disables' these people on top of their impairments.

People with life limiting conditions may be seen as experiencing a 'personal tragedy' by family, friends, and professionals but refute this stereotypical label themselves.

Conclusion

It is frustrating finding funding to support meaningful service user involvement in research. It is far from an equal playing field. Researchers are very privileged in terms of funding and opportunities.

We need to analyse the joint working in this project but it seems clear that there have been benefits for all concerned and it has enabled this research to remain very focused on service user concerns.

References

Small, N., & Rhodes, P. (2000) Too ILL To Talk? User involvement and palliative care. London, UK: Routledge