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Relationship and trust as a vehicle to improved health outcomes: A qualitative study of a Primary Health Care Programme for Travellers

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Abstract

Rapid changes in the control of health and social services have led to the increased adoption of narrow practice approaches driven by contemporary funding priorities, often running contrary to the wisdom, accumulated knowledge, experience, evidence and ethics of social and community development approaches. The Primary Healthcare Programme (PHCP) for Travellers has been developed nationally over the past two decades with the aim of improving the health of the Irish Traveller community. A particular emphasis has been placed upon the provision of health promotion, information, support and outreach through a range of peer delivered community based approaches. This study took place within one such PHCP for Travellers in County Offaly which found itself under increasing pressure from funders to prioritise nationally driven programmes over locally driven community-responsive work. Specifically, questioning the value of more supportive, relational interventions such as *emotional support* whilst encouraging the delivery of interventions which produced statistical information aligned to national health operational plan targets, which the funding officers were in turn under pressure to provide to national offices. This study aimed to explore the value of emotional support, relationship building and trust building in relation to the provision of this Primary Healthcare Programme for Travellers, from the perspective of the community members engaging with the programme. The study reflected the value of emotionally supportive relationships expressed by service users and the importance placed upon the subsequent building of trust. Multiple occurrences of positive shifts in health related behaviours, significant benefits to the mental health of respondents and uptake of appropriate support services are reported and discussed. The study suggests that the increased pressure being placed upon social and community practice by management control mechanisms introduced by funding bodies is rapidly eroding the hard earned experience and knowledge accumulated through decades of social and community work. A particularly negative impact upon marginalised groups such as the Traveller community who experience a complexity of health needs is found. Recommendations include a re-investment in relationship and trust building, and in flexible, responsive, community driven responses to achieving national health priorities within marginalised communities.

Keywords: community development; health; relationship; trust; Travellers; primary healthcare.

Context

In the last three decades, the control of health and social services has undergone substantial change. Health and social care providers have extensively been exposed to management control mechanisms that have affected the nature of service delivery. These developments emerged in reaction to several challenges that threatened healthcare systems in Western countries, such as the welfare state crisis, reinforced market requirements (Harrison and Ahmad, 2000) and publicly exposed clinical failures (Weick and Sutcliffe, 2003).

In this context, and with growing demands regarding healthcare accountability and transparency, governments and policymakers searched for more effective and efficient healthcare services (Pickard, 2009). The introduction of management control mechanisms has often been promoted by the new public management movement as a means of aligning the diverse or conflicting interests of managers and stakeholders, reflecting trends in the broader public sector (Leicht et al., 2009). These developments have contributed to an increased implementation of management systems that have been employed by healthcare organisations (Numerato et al., 2011) and subsequently enforced upon funded partner organisations.

Lenette & Ingamells (2014) argue that the field of human services is increasingly adopting narrow practice approaches, driven by contemporary funding priorities. Such approaches reflect a reductionist understanding of human need, and run contrary to the wisdom, accumulated knowledge, experience, evidence and ethics of social and community development work. They call for a broader funding paradigm that values social and community knowledge and practice, and a respect for local context which enables on-going responsiveness and adaptability accordingly. It is within this context that this study was conceived.

Health outcomes for members of the Irish Traveller Community

Irish Travellers are a small indigenous ethnic minority group that has been a part of Irish society for centuries. They possess a value system, language, culture and traditions based around nomadism which make them an identifiable group both to themselves and others (All Ireland Traveller Health Study, 2010). To date, there has been a refusal by the Irish Government to officially recognise Travellers as an ethnic group and this is reflected in the policies, programmes and institutional practices that impact on the Traveller community (Equality Authority, 2006). The evidence clearly shows that such minority groups experience significantly higher levels of physical and mental ill health, discrimination and racism than the majority population (Naidoo and Wills, 2000). The Traveller community is widely acknowledged as one of the most marginalised and disadvantaged minority groups within Irish society (Combat Poverty Agency, 2003).

The gap between the health status of Travellers and that of the settled population is startling. Life expectancy is 15 years less for Traveller men in comparison to the majority population and 11 years for Traveller women. The suicide rate is 6.6 times higher for members of the Traveller community than the rate for the majority population (All Ireland Health Study, 2010). In an attempt to address these health inequalities, a

number of specific policies and strategies concerning the Traveller population were adopted by the Health Service Executive (Traveller Health Unit, 2004).

Primary Healthcare Programmes for Travellers

Arising out of the Alma-Ata Declaration (World Health Organisation, 1978), the *Primary Health Care* model was introduced in order to support the World Health Organisation's *Health for all* initiative. The Primary Health Care model has since been universally adopted as an approach to health service delivery within community settings. In the Irish context the Primary Health Care model has been identified and widely adopted as an innovative approach to health care within communities with the values of empowerment, partnership and advocacy at its heart (Traveller Health Unit, 2004). Such values closely reflect those of community development work (Community Workers Co-operative, 2004). This community development approach to health underpins health promotion activity and tackles health inequalities. It is seen as crucial to long term outcomes and progress.

Combining the values and approaches of the Primary Health Care and Community Development models are the Primary Health Care Programmes (PHCP) for Travellers. The first of these projects was initiated in 1994 as a joint partnership of the former Eastern Health Board and Pavee Point, a Traveller led community development organisation (All Ireland Traveller Health Study, 2010). The HSE Traveller Health Unit was established in 1998 and is responsible for administering the funding for these programmes and developing effective, equitable and sustainable health care to Travellers. The PHCP for Travellers model has been widely replicated as a range of peer led initiatives across Ireland, employing Travellers as Community Health Workers (Traveller Health Unit, 2004). Evidence suggests that this approach has been successful in engaging the Traveller community with a range of health services (All Ireland Traveller Health Study, 2010).

The study

The Tullamore Traveller Movement was launched in 1996 as a response to the needs of the local Traveller community. The organisation has since become the Offaly Traveller Movement (OTM) and continues to work for Traveller rights and social justice throughout the county. It is a community development organisation offering services responding to health, accommodation, youth, education and human rights. The work of the Offaly PHCP for Travellers commenced in 2003 through a partnership between OTM & the Health Service Executive (HSE). The work has a Primary Health Care ethos which is rooted in a community development, peer-led model as outlined previously. The Offaly PHCP for Travellers provides a range of information, advocacy and networking roles, with the aim of improving the health of Travellers, including access to health services, policy development and lobbying and monitoring on behalf of Travellers. A particularly important role is given to the provision of health promotion, information, support and outreach work with Travellers delivered through community based approaches to health.

OTM found that the Offaly PHCP for Travellers was under increasing pressure from the local HSE Traveller Health Unit (THU) funding body to prioritise work plans designed to produce data aligned to targets within national health strategies such as the HSE

National Operational Plan 2013 (Health Service Executive, 2013) at the expense of more locally driven, community-responsive work. Specifically, the THU questioned the value of statistics which reflected more supportive, relational interventions such as *emotional support*, and encouraged statistical information aligned to HSE Operational Plan targets such as breast cancer screening, cervical cancer screening, heart health and child immunisation. The local THU in turn was under pressure to provide this statistical information to regional and national HSE offices. There was an expectation from the local THU that the Offaly PHCP for Travellers would design its work plans to align with such targets at the expense of activities falling outside of these target areas.

Although this paper focuses upon the HSE funding relationship, the Offaly Traveller Movement reported to the research team a clear shift by the majority of its funding partners in recent years towards target based service provision, away from responsive community based approaches. A particular concern for OTM and many other Irish community development organisations is the 2015 launch of the Social Inclusion and Community Activation Programme (Department of Environment, Community and Local Government, 2014) which will set all of its targets at national level, to be implemented locally. In a study exploring financial reporting by non-profit organisations to government funders (Flack & Ryan, 2005, p. 69) it was found that such an emphasis upon 'upward and external' accountabilities serves as a functional and control tool on the sector. This subsequently hinders the development of 'downward and internal' mechanisms of accountability which are necessary for a meaningful strategic response to the needs of specific communities.

In fact, the current Healthy Ireland framework for improved health and wellbeing 2013-2025 (Department of Health, 2013, p. 24) clearly outlines the value of relationship as a vehicle to improved health outcomes: 'The impact of positive social interaction cannot be underestimated. Social interaction and supportive social connectedness and involvement in community life are a keystone to empowering people at the individual level and building strong communities for health and wellbeing'. In its National Intercultural Health Strategy 2007-2012, the Health Service Executive also states that NGOs are 'well positioned to be aware of the issues affecting access to healthcare and are able to be flexible in the ways that they respond to the emerging and existing needs of members of diverse cultures and ethnic groups' (Health Service Executive, 2008:96). Unfortunately, the opportunities for implementing the good practice guidelines contained within these health strategies are often unrealised as systemic pressure to meet key targets creates a focus upon the implementation of programmes which produce data aligned to these targets, at the expense of more innovative practice models.

The collection of data on the provision of emotional support through the Offaly PHCP for Travellers had been integrated into the OTM data collection system in order to communicate the centrality of relationship and trust building to the peer led approach adopted, and reflect the resources necessary to deliver this core aspect of the programme. A total of 998 individual interventions involving emotional support were recorded by the Offaly PHCP for Travellers in 2013 (Offaly Primary Healthcare Programme for Travellers, 2013), alongside 360 interventions concerning cervical cancer screening, 127 interventions concerning breast cancer screening, 451 interventions concerning child immunisation, 560 interventions concerning smoking

cessation and 1072 interventions providing nutrition and lifestyle advice. All of these interventions are in line with national health strategic priorities. Furthermore, anecdotal evidence from the Community Health Workers (CHWs) suggested that the implementation of such health interventions were in fact dependent upon the relationships and trust developed through the provision of long term emotional support. This study therefore aimed to explore the value of emotional support, relationship building and trust building in relation to the provision of a Primary Healthcare Programme for Travellers, from the perspective of the community members engaging with the programme.

Methodology

Sixteen semi-structured interviews were conducted in February 2014 over a two week period with individuals who engage with the Offaly PHCP for Travellers through the PHCP social club. All forty five members of the social club who also received individual support from the PHCP for Travellers were informed about the study. The sample group represents the 16 group members who consented to participation in the study, the specific nature of the study necessitating the purposive nature of the sample group. Respondents represented the areas of Tullamore, Killeigh, Clara, Birr and Banagher. The sample group consisted of 14 female respondents (ages 22-62 years) and two male respondents (ages 43 and 64 years).

Areas explored included the value of Community Health workers spending non clinical, relationship building time with service users, trust building, subsequent improvements in mental or physical health experienced and changes in health behaviours. Interviews lasted an average of 35 minutes. Initially, the data collected was transcribed and analysed using a process of thematic analysis (Ryan and Bernard, 2003; Grbich, 1999). These themes were then further developed to gain more depth and richness of understanding. A draft of the findings was subjected to a member-checking process involving the research team (the co-authors and a research assistant from the local Traveller community) and three respondents to promote rigour and ensure the interpretation of data had credibility and trustworthiness (Rice and Ezzy, 2005).

This has been a small study involving participants specifically from the Traveller community in County Offaly. It has examined what might be common experiences for many health service users, but in a specifically Traveller context. The findings of this study then, by their nature, have produced insights about particular situations, some of which might not be transferable beyond that local and cultural context, but a number suggesting implications far beyond the Traveller community itself.

Ethical Issues

For those who wished to participate in the research study a consent form was provided. Information sheets and consent forms were also read to participants in order to address literacy needs. Only the researchers had access to the original personal information of the research participants. Both female and male researchers were available for data collection in order to address potential gender dynamics limiting the freedom of respondents to fully participate in this study.

Themes

Relationship building

All respondents reported that the time spent by CHWs on building emotionally supportive relationships was highly valued. One respondent reported that:

Without the CHWs I don't know where I'd be. I'd be on Prozac a long time ago. We just sit there and talk about stuff I can't tell my husband. My daughters are the same. My daughter found out when she was 18 that she was pregnant. The only one she spoke to was the CHW. It was the CHW that told me (F, 43 years).

Another respondent explained:

My husband died three years ago, my CHW- she knew all the family and knew me. Very hard to describe what she gives us, but don't think we could have got on without her, she knew us all so well, knew children since birth (F, 61 years).

Another respondent described such emotional support as:

Very important, there's times when you can't make that phone call yourself, you're so emotionally beat up, it's good to pick up the phone and it's not your family. [CHW's] know the way to help. So it may be financial worries or feud fighting. Traveller women in particular have a lot of worry, it's very important to have someone to talk too, very important that it's non-judgemental, not part of the troubles or whatever is going on (F, 41 years).

The importance of trust

The importance of the trust developed through such supportive relationships was also described as highly valuable by the majority of respondents. One respondent explained:

I wouldn't have anyone coming into my home that I didn't know. [CHW 1] is great, there's not a week that hasn't gone by that she didn't ring me. There's three people, [CHW 1], [CHW 2] and [CHW 3] that I can open to. I would be very isolated without them, the things I am going through. I am taking care of my grandchildren and have heart problems (F, 51 years).

Other respondents mirrored this view and stated that:

It would devastate me if a stranger came out to my home. Like they understand where we're coming from, our values, our culture. I can be myself [with the CHW], there's no big words, someone like from the HSE or social workers couldn't be like that (F, 34 years).

I wouldn't have gone [for a smear test] without that trust. I put it off for five to six years. If I hadn't gone when I did God knows what would have been the case (F, 40 years).

There was a stage when my CHW organised counselling for me. Now, I wouldn't have believed in counselling, talking to a stranger. Without her and taking her word I wouldn't have done it (F, 61 years).

Immediate health benefits

A clear theme throughout the study was the correlation between the development of emotionally supportive relationships and immediate benefits to health and in particular mental health. Respondents stated that:

[I was] very depressed at some stages, I had my husband's illness, my sister's and my parents. On your darkest day, if you have a chat and a cup of tea ... it can lift your darkest day (F, 41 years).

I have two daughters dead and one son by suicide. They [CHWs] spend time with me. I got bad one morning, they looked after me. I was in the right place (M, 64 years).

This time last year I was very isolated, I couldn't come out [of my home] then. Only for them [CHW's] am I here. I can speak to them about my problems, stop me going into myself again (F, 51 years).

Changes in health behaviour

A central finding of this study is that health outcomes in line with national programme priorities were reported to have occurred *as a result* of the development of emotionally supportive relationships with the CHWs. A number of respondents described how such relationships had influenced their health behaviours resulting in early detection of life threatening illness and successful treatment:

I was years not going for a smear test and they kept at me and at me and eventually I went there. I wouldn't have gone without them at me. I missed several appointments, but they kept making more. Only for them, I did go and they found cells, four of them and then four more. Had biopsy and other treatments. I'm still in the treatment programme, not finished yet (F, 40 years).

I'm 47, I never went for smear tests. I was ashamed of my life. My CHW talked me into going through with it. She also talked my daughter into going. She would be dead only for that. The CHW held her hand. She got a letter after saying she needed a second appointment. She got cells lasered off. It was my CHW that saved her life, simple as that, just by talking. There are not enough hours in the day to praise them (F, 47 years).

There were also reports of seeking and engaging in treatment via mental health services, made possible by trust developed through long term emotionally supportive relationships:

Now I have an appointment with a counsellor because I suffer from depression. I wouldn't have got this far without the support I received from the CHWs (F, 32 years).

A couple of years ago, I did something I never would have before, I visited a counsellor. I never would have been able to sort it out myself at the time [without the support of a CHW] (F, 34 years).

Respondents also reported significant positive change in health awareness and lifestyle choices, directly linking such change to the relationship and trust built with the CHWs:

Before [developing a relationship with the CHW] I didn't understand about getting my bloods taken, now I go once a year. I go to the dentist now too for routine check-ups. I was a person that didn't go anywhere. My interest in fitness has come from [CHW 5]. If she didn't push me to go swimming I couldn't have known about this great experience. I now do 5km races. I completed a triathlon last year, it was great. I am competing in the half marathon this year. I done a 5km run yesterday in 20 minutes. I am running for about a year. It has changed my life (F, 22 years).

Discussion

The study clearly shows the high regard in which the CHWs are held by members of the Traveller community engaged with the Primary Healthcare Programme, with a specific emphasis upon the value of emotionally supportive relationships and the subsequent building of trust. Whilst the immediate benefits to wellbeing reported as an outcome of relationship and trust are positive findings in themselves, the multiple occurrences of significant positive shifts in health related behaviours reported in this study are highly encouraging. The participant experiences mirror those reported in earlier studies of emotional sustenance as a mode of support delivered by supporters who are experientially similar to the recipient of support. For example, Thoits (2011) found that emotionally sustaining behaviours, empathy, active coping assistance, and role modelling from similar others can be highly efficacious in alleviating the physical and emotional impacts of stressors.

Also supporting the findings of this study, in a review of data from the All Ireland Traveller Health Study, McCorrigan et al. (2012) made comparisons with survey data from the INSIGHT 2007 Survey and a nationally representative sample of the Irish general public entitled to means tested general medical services. Valid responses were provided by 1,947 Traveller respondents (32.5% males). They described significantly poorer quality health care experiences than did the comparator population, with fewer Travellers expressing trust in health service providers. This mistrust is often fuelled by a sense of devalued identity, and experienced as a sense of shame and humiliation. Adverse health service experiences are often attributed to discriminatory lack of care based upon their ethnic identity. This in turn leads to a lowering of expectations, and the adoption of various strategies to manage health for as long as possible without making contact with health services.

Furthermore, in a study of the healthcare needs of the Traveller community across the UK & Ireland (Van Cleemput, 2000) it was again noted that the Traveller communities mistrust authority; and this was seen as an understandable attitude given their history of centuries of persecution and continued discrimination. They were found to often question the motives of those working with them, which correlated to a clear reflection of the way that they expect to be viewed. The study expressed the importance of the relationship building process within Traveller health programmes, with clear findings that “when trust is gained, more intimate health concerns will be discussed” (p. 36). Similarly, in a study of the effects of emotional support within the African American

community it was found that perceived emotional support was associated with lower odds of suicide ideation and suicide attempts (Lincoln et al., 2012). In the Traveller community during the period 2000 - 2006 the rate of suicide was over three times that of the total population. Peaking in 2005, it was over five times the national rate (Walker, 2008). Evidence from this study that the emotionally supportive relationships developed with CHWs directly improve mental health is certainly worthy of further study.

Ever increasing control mechanisms introduced to align social and community practice to the interests of statutory funding bodies is rapidly eroding the hard earned experience, knowledge and ethics accumulated through decades of social and community work, with a particular negative impact upon marginalised groups such as the Traveller community who experience a complexity of health needs. A reflection upon the findings of this and similar studies might offer an opportunity for policy makers to discover that exclusively focusing upon the roll out of narrow practice approaches linked to national strategic priorities, without a complementary investment in (and valuing of) emotionally supportive relationship, trust building and community driven, local responses, is in fact a false economy. The positive health outcomes found in this study are exactly in line with current national health priorities, and the evidence shows that these outcomes were only made possible through relationship, trust and a local responsiveness.

Recommendations

A rediscovery of the value of relationship and trust building, and provision of the non-programme specific time required to realise this should be examined by health funding bodies, allowing for more organic, community driven practices to emerge. In the case of the Traveller Health Units, this has been clearly prioritised through the primary health/community development approach taken to Traveller health in the past two decades, but as discussed, increasing pressure to roll out national health initiatives en masse is resulting in a deviation from such approaches in favour of more prescriptive, narrow practice requirements with a focus upon numerical data collection.

Given the findings of this study it is recommended that further research into these themes is undertaken in order to create an evidence base which could be utilised to impress upon health policy makers the absolute necessity of investment in relationship and trust, and in flexible, responsive, community driven responses to achieving positive health outcomes within marginalised communities. The design of data systems to evaluate such approaches may be conducted in tandem. For policy makers who may be far removed from actual service delivery, this could prove to be enlightening. As Mosse (2004) argues “development proceeds not only (or primarily) from policy to practice, but also from practice to policy” (p. 658).

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Biographical notes

Matt York is a development practitioner and researcher who has worked in the fields of homelessness, mental health, primary healthcare and community development in the UK, Ireland and South Africa. He is a founder and trustee of the Mandala Trust which partners with grassroots community organisations supporting children in vulnerable situations internationally.

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