



What is the mechanism effect that links social support to coping and psychological outcome within individuals affected by prostate cancer? Real time data collection using mobile technology



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ABSTRACT

Purpose: Unmet support needs are prevalent in men affected by prostate cancer. Moreover, little is known about the optimal type of social support, or its mechanism effect between coping and emotional outcome in men affected by this disease to identify areas for clinical intervention. This study aimed to empirically test the propositions of social support theory in “real time” within individual men living with and beyond prostate cancer.

Methods: Purposeful sub-sample from a larger prospective longitudinal study of prostate cancer survivors, took part in real time data collection using mobile technology. Self-reports were collected for 31 days prompted by an audio alarm 3 times per day (a total of 93 data entries) for each of the 12 case studies. Electronic data were analysed using time series analysis.

Results: Majority of response rates were >90%. Men reported a lack of satisfaction with their support over time. Testing the propositions of social support theory “within individuals” over time demonstrated different results for main effect, moderation and mediation pathways that linked coping and social support to emotional outcome. For two men, negative effects of social support were identified. For six men the propositions of social support theory did not hold considering their within-person data.

Conclusion: This innovative study is one of the first, to demonstrate the acceptability of e-health technology in an ageing population of men affected by prostate cancer. Collectively, the case series provided mixed support for the propositions of social support theory, and demonstrates that “one size does not fit all”.

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1. Introduction

Prostate cancer is a major health burden in Europe (Jemal et al., 2011). The disease and its treatments have the potential to cause substantial short- and long-term problems for men affected by prostate cancer (Davis et al., 2014). The delicate nature of treatments mean that men with prostate cancer often face a host of difficulties which can negatively affect Health-Related Quality of Life (HRQoL) (van Tol-Geerdink et al., 2013), including physical and psychological problems (Cockle-Hearne et al., 2013; Ream et al., 2008). Toxicities associated with prostate cancer treatments

include: urinary (urgency, frequency, incontinence) (Zelevsky et al., 2008), bowel (rectal bleeding, urgency in defecation, diarrhoea, and faecal leakage) (Fransson et al., 2006) and sexual dysfunction (impotence, loss of libido) (Shikanov et al., 2008). Other physical symptoms associated with therapies include: fatigue, weight gain, osteopenia, anaemia, muscle atrophy, gynaecomastia, and hot flushes, and psychological problems including anxiety, depression and loss of cognitive function (Carter et al., 2011). Due to increasing survival rates (Jemal et al., 2011) the number of men dealing with the aftermath consequences of prostate cancer are set to rise, currently 250,000 men in the UK alone (Prostate Cancer UK, 2014).

For many patients and family members, a diagnosis of prostate cancer can lead to many ambiguities, such as whether the cancer will recur, whether the cancer will prove fatal, or will it lead to permanent physical problems and disability. For these reasons, and for many others, the experience of prostate cancer is uniquely

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stressful; and social support has been demonstrated to be beneficial in coping with prostate cancer's associated stressors (Roberts et al., 2006). Social support for many individuals is an intuitive term that is used to describe help that is received from others in a difficult situation. There is a substantial body of social support literature, as yet there is not a single consensus on the definition of social support (Hupcey, 1998), but an important distinction is that social support is a multi-faceted construct (Paterson et al., 2013). That is to say, social support can be measured as perceived social support and received social support (Cohen et al., 2000; Schwarzer et al., 2003). Perceived social support is a construct that is used to describe social support anticipated prospectively at a time of need sometime in the future (Procidano and Heller, 1983), whereas received social support is based upon retrospective accounts of received social support (Barrera et al., 1981). Perceived and received social support constructs can be further distinguished by the following types of social support: emotional, informational, and instrumental (Cohen et al., 2000). Social support is associated with improved HRQoL for cancer survivors (Helgeson, 2003) and the mechanisms underlying such links can be explained by the propositions of social support theory.

There are two dominant theoretical frameworks that link social support to improved physical and mental well-being: the Main Effects Model and the Stress Buffering Model (Cohen and McKay, 1984). According to the main effects model, people with high social support (perceived or received social support) have better physical and mental health compared to those with low social support, regardless of the levels of stress (Cohen and McKay, 1984). The relationship between social support and HRQoL is believed to be linear for the main effects model (Helgeson, 2003). Whereas, the stress buffering model states that social support (perceived and received social support resources) is associated with improved physical and mental health only when individuals are exposed to stressful conditions (Cohen et al., 2000). Thus, under conditions of high stress, social support is believed to act as a buffer (moderator variable) against the adverse effects of that stressor. The term "buffering" is used because it is believed, according to buffering model, that social support lessens the pathogenic effects of a stressor, for example, a cancer diagnosis or living with sexual dysfunction. The stress buffering hypothesis states that coping performances are enhanced when social support (Cohen et al., 2000) is high, and is very closely related to Lazarus and Folkman's (1984) theory on stress and coping.

Coping can generally be defined as cognitive and/or behavioural attempts to manage situations that are appraised as stressful to an individual (Roesch et al., 2005). Coping has been defined as "constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of a person" (Lazarus and Folkman, 1984). The transactional process of stress and coping theory dominates social support research (Lakey and Orehek, 2011) and details the central importance of social support on improving emotional outcome for prostate cancer survivors (Zhou et al., 2010a, 2010b). The propositions of social support theory suggest that social support may operate through main and moderation effects, but existing social support theoretical models do not explicitly detail the possibility of mediation effects, i.e. that coping is related to emotional outcome because of social support, see Fig. 1.

The importance of social support as a resource for people affected by cancer is not a new concept, but specifically, prostate cancer survivors have reported a lack of support for their unmet physical and psychological problems (Cockle-Hearne et al., 2013; Paterson et al., 2015; Ream et al., 2008). Therefore, understanding the mechanism effect of how coping and social support operate on emotional outcome over time has the potential to help to identify

men who are at high risk of inadequate support provision and suggest directions for intervention (Paterson et al., 2013). Moreover, further work is needed to understand and assess whether the severity of prostate cancer stage (localised, locally advanced and metastatic) affects the mechanism effect of social support.

To date, literature examining the mechanism effect that links coping, social support and emotional outcome in men affected by prostate cancer is restricted to aggregate group level effects, i.e. between-person effects (Mehnert et al., 2010; Paterson et al., 2013, 2014; Zhou et al., 2010a, b), and has neglected the importance of *within-person* experience and change over time. Therefore, existing literature has primarily employed between-subject designs, which only accounts for the variability between study participants. Many psychological theories, including the propositions of social support theory (Cohen and McKay, 1984; Cohen et al., 2000), describes the process that occurs within individuals and therefore, existing evidence to date may not adequately test the underlying within-person mechanisms proposed by social support theory.

Case-based (n of 1) time series studies (Molenaar, 2004) can form the *pre-clinical and theoretical modelling* stages of the Medical Research Council's framework for complex interventions (Craig et al., 2008). The first step in designing a complex intervention is to establish the theoretical basis that suggests that a future intervention may have the effect(s) expected. Therefore, case-based time series methodology is low-cost and has the potential to be very effective in facilitating the early development stages of interventions. Moreover, a further advantage to using this approach is that the electronic diary data are collected in real time, which is date and time stamped (at the time of data entry), and therefore minimises the risk of introducing retrospective memory recall (Stone et al., 2004, 2003; Stone and Shiffman, 2002). Empirically, testing within-person change over time has the potential to demonstrate the optimum types of social support that influence emotional outcome for men living with and beyond prostate cancer. Thus, applying theoretical constructs using a within-person design is likely to enrich and enhance tailored interventions focussed at the individual level of change (Borckardt et al., 2008). Therefore, this study aimed to address the following research question: does social support (perceived, received and satisfaction level) moderate/mediate the relationship between coping and negative affect within individuals affected by prostate cancer?

2. Methods

After ethical approval was granted (10/S1402/7) this study recruited participants from two teaching hospitals in the UK using the following inclusion criteria: confirmed diagnosis of prostate cancer (PC) all stages and treatments, before radical PC treatment commenced, ability to read and write English, and able to give informed consent. Exclusion criteria were those individuals unable to meet the inclusion criteria or those patients identified by their clinical care team to be physically or psychologically unfit to take part in the study. Recruitment took place at 2 hospital out-patient settings, and demographic and clinical data were collected. Participants were asked to complete validated questionnaires at baseline (before radical treatment) and at six month follow-up (but these data are published elsewhere Paterson et al., 2014). A subsample of men (n = 12) were asked to complete an electronic behavioural diary which captured real-time patient reported outcome measures.

A small handheld PDA with diary software was used for each of the 12 study participants. The electronic behavioural diary (Dell Axim X51) was supported by Pocket Interview software (Morrison et al., 2009) and data was encrypted using the RC4 cipher (Morrison et al., 2009). This type of methodology has not been applied to

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