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The interweaving of pharmaceutical and medical expectations as dynamics of micro-pharmaceuticalisation: Advanced-stage cancer patients' hope in medicines alongside trust in professionals

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ABSTRACT

Existing pharmaceuticalisation research denotes the salience of expectations in novel medicines and in the medical contexts through which these may be accessed. Specific processes of expectation such as hope and trust, alongside their shaping of patients' lifeworlds around pharmaceutical use, remain neglected however. Considering data from in-depth interviews and observations involving thirteen patients with advanced-stage cancer diagnoses who were or had recently been involved in clinical trials, we develop an interpretative phenomenological analysis of the influence of hope and trust upon the accessing of novel medicines through trials, illuminating the depth and texture of pharmaceuticalisation at the micro-level. Trust in clinicians and hope in trial medicines, for self and future patients, were important in the reconfiguring of patients' horizon of possibilities when accessing new medicines. Interwoven processes of trust and hope, embedded within heightened vulnerability, sustained the bracketing out of doubts regarding medicines, trials and professionals. The need to maintain hopes, and trusting relations with professionals who facilitated these hopes, generated meaning and momentum of medicines use which inhibited disengagement from trials. Findings indicate the taken-for-granted, as well as more reflexive, pursuit of solutions through medicines, which in this case-study enabled the generation of evidence through trial involvement. Analyses of micro-level dynamics within both downstream-consumption and upstream-substantiation of pharmaceutical solutions assist more nuanced accounts of interests, agency and expectations within pharmaceuticalisation.

1. Context: micro-level pharmaceuticalisation amidst vulnerability and uncertainty

The relationship between pharmaceuticalisation and medicalisation is central to recent debates around both concepts (Barker, 2012; Bell and Figert, 2012; Coveney et al., 2012; Conrad, 2013). Since the early-1970s medicalisation studies have sought to analyse the recasting of human problems as medical ones, with medicinal products (from here on 'medicines'), alongside other treatment options, a common feature of proffered *solutions* (Conrad, 2013). The concept of pharmaceuticalisation has emerged more recently to reflect nuances on and divergences from this classic theme, not least due to: increasing marketing influence of pharmaceutical companies, amidst lighter regulation, via internet and other media (Abraham, 2010); an apparent emergence of more autonomous consumer-patients (Conrad, 2013); the use of medicines beyond the prescribed influence of healthcare professionals through more products becoming available over-the-counter (Abraham, 2010) and, moreover, the use of certain medicines for non-medical "enhancement" purposes (Williams et al., 2011; Conrad, 2013). Pharmaceuticalisation thus involves the "redefinition and reconstruction" of certain problems as having a "pharmaceutical solution" (Williams et al., 2011,p.712), whereby this process may or may not involve medical professionals (Coveney et al., 2012) and in some respects appears increasingly independent of them.

These tendencies in medicines usage – increasingly "disembedded" (Giddens, 1990) from specific care contexts and

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medical relations, expanding into more areas of everyday life (Fox and Ward, 2008) – are unsurprising given the profoundly late-modern contexts in which medicalisation and pharmaceuticalisation are located (Britten, 2008; Bell and Figert, 2012). Yet while pharmaceuticalisation is most legible on the margins of the medical and beyond, Abraham (2010) warns against the neglect of processes taking place within more established medical institutions. Abraham (2010,p.602) contends that if studies of pharmaceuticalisation are to proceed beyond merely describing the creeping frontiers of medicines use, then the qualitative processes which drive pharmaceuticalisation, not least biomedical research (including trials), require interrogation. A preoccupation with pharmaceuticalisation outside medical contexts has led to a partial disregarding of enduring roles of medical professionals within the ongoing redefinition and reconstruction processes of many problems and solutions through medicines. This forms part of a more general neglect of micro-level relations and interactions within many pharmaceuticalisation discussions.

Medicine as an institution, and professionals who advise on pharmaceutical use, remain salient to understandings of pharmaceuticalisation (Coveney et al., 2012:161). Even where medicines are used outside medical contexts, a broader medicalised lifeworld or "medical imaginary" (Good et al., 1990; Good, 2001), alongside related perceptions of the body as technical and modifiable (Shilling, 2012; Barker, 2012), are relevant in shaping more conscious or "natural" attitudes (Schutz, 1972) towards medicines usage. Within and beyond medical contexts, changing modes in which bodies, pathologies and medicines are understood by experts and ways in which this knowledge is conveyed to and interpreted by patients/consumers is highly relevant to the *depth* (taken-for-grantedness) and *texture* (meaning) of pharmaceuticalising reconstructions and redefinitions, alongside changes in *breadth* (widening/shrinking usage). For example, paracetamol treatment for headaches follows deep pharmaceuticalisation in some contexts, while usage of erythropoietin (EPO) amongst professional cyclists has moved from novel (shallow) to normal (deep) to moot (shallow again). Meanwhile manifold contrasting meanings are ascribed by different users.

Cancer care is one context where medicalisation and pharamceuticalisation are *prima facie* accomplished, but where the breadth, texture and depth of pharmaceuticalisation remain fluid and iterative. Novel use of existing medicines, for example thalidomide in managing advanced cancers, with corresponding reductions in transfusion-dependence (eg Eleutherakis-Papaiakovou et al., 2004), demonstrates further *broadening* pharmaceutical redefinition of treatments. For patients with advanced-stage diagnoses and limited prognoses, choices may exist for using medicines towards either more curative or palliative ends (Good, 2001), raising issues of different *textures* (meanings) of pharmaceutical solutions (Coveney et al., 2012). Issues around the *depth* of pharmaceuticalisation – the relative taken-for-grantedness (confidence) or reflexive questioning of the appropriateness of particular pharmaceutical solutions – are pertinent to participation in pharmaceutical trials, which often take place at or beyond the limits of curative solutions, where uncertainty is heightened.

Exploring such depth and texture, albeit in novel transplantation interventions, Good (2001) emphasises how broader investments – for example of money and emotions – in constructing a patient's horizon of possibilities (lifeworld), leads to the structuring of affective dispositions and treatment decisions. In this way national cancer cultures impact at the micro-level in orienting "clinical narratives" (Good, 2001:pp.397,399) – the dynamics of interactions and related understandings as these develop over time. If, following Simmel, we consider that wider social processes are vitally illuminated at the level of individual action (Schutz, 1972,p.4), detailed exploration of these lifeworld-assumptions and related decisions to adopt particular medicines as solutions are fundamental to understanding broader pharmaceuticalisation.

Lifeworlds, narratives and decision-making about (cancer) medicines are often defined by experiences of vulnerability amidst uncertainty (Bissell et al., 2001; Broom and Tovey, 2008). Doubts regarding safety, effectiveness and unforeseen impacts may mean that medicines are perceived as problematically risky (Abraham, 2010). Yet vulnerabilities experienced as medical problems and a lack of perceived alternatives may compel actors to recast potentially dangerous medicines as acceptable "options" (Bissell et al., 2001). The practices through which patients evaluate, or implicitly assume, the benefits and/or risks of medicines in such contexts are under-researched (Benson and Britten, 2002) yet crucial to the pursuit of medicines as solutions. As explored below, processes whereby uncertainties are "bracketed" (Möllering, 2001) to the margins of a person's horizon of possibilities (lifeworld), by focussing upon positive futures, can be analysed in terms of trust in prescriber and/or hope in product or outcome (Benson and Britten, 2002; Britten, 2008).

Trust and hope, in managing vulnerability amidst uncertainty (Zinn, 2008), are pertinent for a more nuanced theorisation of users' "interests" around medicines (van der Geest et al., 1996), especially in analysing how interests and decision-making emerge within interactions with experts. Trust, in science (Broom and Tovey, 2008) and in individual clinicians (Corrigan, 2003; Britten, 2008), has been seen to shape decisions regarding medicines use. Furthermore the development and internalising of certain desires shapes the micro-politics of patients' "investment" in new technologies (Good, 2001; Novas, 2006), with different regimes and configurations of hopeful expectations importantly structuring conceptions and pursuits of potential treatment solutions (Brown, 2005; Snowdon et al., 2006).

Uncertainty and vulnerability around medicines use may be especially elevated for cancer patients considering involvement in clinical trials. The format, wording and emphasis of information-giving, "mediated" by evidence-based medicine (Sinding et al., 2010), shapes expectations and thus perceived interests, bearing decisively on patients' decisions. Misunderstandings (Corrigan, 2003), evolving interpretations (Heaven et al., 2006; Snowdon et al., 2006) and various clinical and non-clinical relationships are each influential upon patients' assumptions and conceptions of trial participation; whereby "autonomous decision-making" and "autocratic paternalism" are simultaneously apt descriptions (Corrigan, 2003,p.772). The hopes generated within these structured lifeworlds (Snowdon et al., 2006) alongside the trust that underpins, but which may also be challenged by, ongoing interactions between trial/healthcare professionals and patients (Jenkins and Fallowfield, 2000; Corrigan, 2003) have been acknowledged but not researched in depth. These processes and their shaping of medicines access via trials form the focus of the analysis below.

2. Theoretical framework: bracketing off uncertainty in medicines-use through trust and hope

Futures and expectations regarding healthcare technologies, particularly their material embeddedness (eg Good, 2001; Brown, 2005; Novas, 2006), have become important research topics, though pharmaceuticalisation studies have tended not to distinguish differing formats of expectation such as trust or hope. Meanwhile, despite a sizeable literature around trust and healthcare and a growing one on hope within illness contexts, few studies explore the relationship between these two processes, especially as these emerge within patients' lived experiences.