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"She was a little bit unrealistic": Choice in healthcare decision making for older people

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ABSTRACT

This paper examines autonomy, choice, options, and power in healthcare decision making for older people. Using discourse analysis and a case study from data gathered as part of an ethnographic field study we critique a common conceptualization of healthcare decision making as patients choosing from an array of options offered by healthcare providers. A discourse of "giving options and being realistic" used by healthcare providers is contrasted with the experience of a single patient's transitional care from hospital to home after hip fracture. This illustrates how a wide variety of actors, institutions, values, and resources take precedence in determining a discharge destination. While the accounts given by healthcare providers cast patient choice in respectful terms, an ethnographic approach illustrates that the "choices" are structured by a discourse which simplifies the complexity of what is offered and who gets to choose. In the case study the patient's choice was subjugated by expertise and institutional concerns; her options were largely illusory; and her autonomy was "at risk" due to her age, poor health, and limited resources. We use Foucault's ideas about discourse and governmentality to question the scope of agency in healthcare decision making. We argue that the conceptualization of informed patients making autonomous choices acts as "misdirection" which deflects problem solving and discussion away from a productive examination of the differences between healthcare system offerings and client needs. We conclude by posing questions to reorient the debate surrounding healthcare decision making for older adults and recommend a more participatory approach to designing social services.

Introduction and background

This paper challenges a common framing of healthcare decision making — patients are presented with options from which to make informed choices (Ceci & Purkis, 2009; Kaufman, 1994; Murtagh & Hepworth, 2003). An underlying belief in the provision of patient choice obscures the complexity of healthcare decision making, especially for older people with complex health issues. Based on data from a Canadian ethnographic field study with older hip fracture patients, we examine the ways a focus on individual autonomy limits our understanding of complex healthcare decision making.

Literature examining patient autonomy in healthcare decision making falls into two broad arguments. The first argument is predicated on a respect for patients' rights to autonomy and self determination (Abramson, 1988; Brindle & Holmes, 2004; Coulton, Dunkle, Haug, Chow, & Vielhaber, 1989; Dubler, 1988; Guadagnoli & Ward, 1998; Stacey, Henderson, MacArthur, & Dohan, 2009). The second argument emphasizes networks of actors who negotiate decision making, critiquing the argument which delegates the onus of

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decision making responsibility to individuals (Cartier, 2003; Dill, 1995; Dunér & Nordström, 2010; Funk, Stajduhar, & Purkis, 2011; G. Huby, Brook, Thompson, & Tierney, 2007; Huby, Stewart, Tierney, & Rogers, 2004; Jolanki, 2009; Morgan, Eckert, Piggee, & Frankowski, 2006; Proctor & Morrow, 1990). While authors using both lines of argumentation describe similar aspects of the complexity of decision making for older people, their recommendations diverge based on how they predicate their argument. Those emphasizing individual decision making recommend legal and ethical protection via patient rights to prevent coercion. Those conceptualizing decision making as dispersed through networks of actors appeal to dialogue, inclusivity of multiple actors, and negotiation. However, Canada's healthcare and legal system is currently undergirded by traditional bioethics with an emphasis on individual autonomy in healthcare decision making (see the BC Health Care (Consent) and Care Facility (Admission) Act RSBC, Chapter 181, 1996) (Etchells, Sharpe, Walsh, Williams, & Singer, 1996; Kaufman, 1994).

Using Foucault's (1991) theory of governmentality we examine how techniques of government and self are “structuring and shaping the field of possible actions of subjects (Lemke, 2002, p. 3).” In this study, a repetitive narrative identified in healthcare provider (HCP) accounts of “giving options and being realistic” becomes an active, organizing discourse when it engenders checklists, protocols, policies, and specific resource allocation priorities. Most importantly, it structures the discussions and interactions between HCPs and clients. We trace the tenets set out by this discourse — autonomy, options, and choice — to their repercussions for one patient.

We argue that a particular discursive field in discharge planning stabilizes a guiding rationality among HCPs that options are offered to individuals whose duty as a ‘good’ patient is to choose rationally and in their best interest. We outline how the conceptualization behind the ‘giving options and being realistic’ discourse defines the parameters and possibilities for a particular patient and her healthcare team. This ethnographic case study makes visible the seams of governmentality techniques such as expert guidance, “responsibilization" (Funk et al., 2011), and self governance (Foucault, 1991; Lemke, 2002; Lupton, 2006), which usually smoothly guide individuals to make decisions that suit both normative health goals and societal ordering. In this case the experts, frontline HCPs on a multidisciplinary healthcare team (MDT) working in a hospital who were guided by normative processes and policies, controlled and defined the decisions to be made while believing they were offering patient choice. The patient was very aware that she was vulnerable, poor, and dependent on a network of subsidized services, family members, and HCPs. The guidance of expertise combined with the patient's own risk avoidance accomplished a routine care transition, but not without some resistance.

Connecting Foucault's (1991) emphasis on how discourse structures what is considered possible to Freudenburg and Alario's (2007) metaphor of magicians' skills of misdirection, we argue that the discourse “giving options and being realistic” focuses attention on patients' rational decision making and ability to understand the “reality” of their situation as seen by healthcare experts. When there is conflict, the patient is blamed and construed as risky and unrealistic. HCPs and clients are equally frustrated at the process of finding options which suit needs; however, through techniques of expert guidance and self governance the focus becomes how patients need to conform to what exists. This leaves unasked, are the options that exist working, ethical, or appropriate? Freudenburg and Alario (2007) encourage us to look for what is missing from debates which grant processes and situations legitimacy, or “the process of diverting attention away from such uncomfortable questions altogether, by reframing the debate as being ‘about’ something else — preferably about the legitimacy of one's critics (p.161).” In the case of conflict between teams of HCPs and clients during discharge planning, this is a potent approach for understanding how patients come to be talked about as “risky” and “unrealistic.”

Methodology

Multi-site ethnographic field study

We present data and analysis drawn from a larger multi-site ethnographic field study focused on post operative hip fracture care transitions for older people in Canada. Specifically, information exchange between clients and HCPs were examined. Our approach was guided by common principles of ethnographic field studies including reflexivity, reciprocity (Hammersly & Atkinson, 2007), and multimodalities for data generation (Atkinson, 2008). A subset of the data generated in the multi-site ethnographic field study is used in this analysis. Specifically, we draw on data collected in one urban site, located in British Columbia, Canada. We obtained approval from the University of British Columbia and three healthcare authorities' research ethics boards.

Study design and participants

There were two phases of data collection — key informant interviews and a field study. In Phase 1 HCPs in two healthcare authorities involved in care transitions were recruited via email. Initial participants were asked to encourage colleagues to participate in the interviews, which resulted in four more participants. In total seventeen HCPs were interviewed as key informants including three participants from nursing, four from occupational therapy, four from social work, four from physiotherapy and two participants involved in healthcare administration. Participants came from settings along the continuum of care: ten participants work in orthopedic units in hospitals, two participants work in rehabilitation institutions, and five participants work in the community. The key informants were asked to bring documents they used in hip fracture care. Over eighty documents were collected. Several key informant participants were also interviewed during the field study in relation to a particular patient.

During Phase 2 we recruited networks comprised of patients, family caregivers, and HCPs from two hospitals. For patients, we sampled purposively and by convenience from acute and sub acute units in orthopedic wards with the help of HCPs. Our recruitment criteria were patients who were 65 years old or older, could participate in an interview in English, and had recently undergone surgery for hip fracture. All participants were able to give informed consent in writing. At each setting in the patients' journeys an effort was made to interview two HCPs, the patient, and an informal caregiver. Once the patient had been discharged to their permanent