UNDERSTANDING CHOICE IN ASSISTIVE TECHNOLOGY SERVICE PROVISION: CONSIDERATIONS FOR RESEARCH METHODOLOGY

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ABSTRACT

The adoption of choice as a policy principle in disability services reforms warrants research into the practical implications for assistive technology provision. This paper outlines methodological considerations for the investigation of how choice is constructed and experienced in assistive technology provision. It argues for an interpretive approach that considers the interactions between stakeholders and the influence of contextual factors on choices over time. Understanding stakeholders' interpretations and contextual factors that affect their choice behaviors in AT acquisition will assist the interpretation of AT outcomes. It may also assist in efforts to increase the usability of AT services, develop improved service delivery models, and target policy initiatives to support AT provision practices.

BACKGROUND

A lack of consensus on approaches to AT provision and inconsistent access to services and outcomes reported have led to suggestions for greater consumer involvement and choice (Steel, Layton, Foster, & Bennett, 2014). AT can be considered to comprise a range of devices and services that are difficult to commodify (Jordan, 2006), and its provision is therefore a complex phenomenon. Alternatively, choice in AT provision could be approached as a simple one-off transaction between a consumer and a vendor in which cash is exchanged for a device. Such an approach however, is inconsistent with how different individuals perceive AT and experience choice in AT provision. This paper discusses methodological considerations for research into AT provision, using examples from published literature on choice in health and social services to highlight different approaches and challenges.

ASSUMPTIONS UNDERPINNING RESEARCH

Underlying any research hypotheses are assumptions about the nature of the world, that shape methodological decisions and interpretations. This paper asserts that the reality of choice in AT provision is continually being constructed by the interpretations of actors, which evolve over time through social interactions that are contextually embedded. The underlying assumption, or ontological stance, is that instead of a single reality or objective truth, the reality of the social world is emergent and subjective. In contrast, a positivist ontology assumes there is a single objective reality that is independent of human cognition (Wilson, 1970). Research can adopt subjective or positivist stances, but as the literature provides many multiple conceptualizations of AT and experiences of choice in AT provision, a subjective ontology is most appropriate for investigation into AT provision.

Interpretive (or constructivist) approaches assume a subjective reality, and posit that actors perceive meaning and purpose in their own actions and those of others (Wilson, 1970). The subjective reality of AT provision is highlighted in a study on wheelchair provision (Mortenson & Miller, 2008), which found significant differences in factors affecting decision-making of consumers compared to therapists. To compare the perspectives of different stakeholders, interviews were conducted with 14 wheelchair users, 13 wheelchair prescribers, and 7 family members

or caregivers of wheelchair users (Mortenson & Miller, 2008). Qualitative analysis of the interview data identified key concepts and themes, which were triangulated from multiple perspectives and reviewed by six of the participants. While consumers were influenced by aesthetics (e.g. preference for non-medical looking), performance (e.g. wheelchair speed), and (potential) discrimination or stigma when using AT in public, therapists prioritized the risk of skin breakdown when prescribing wheelchairs. Although the study brought together the perspectives of stakeholders with different roles, the authors acknowledged that the participants had not been involved in the same service delivery episodes, thus not allowing for direct comparison of stakeholder perspectives.

Critical approaches to research are also subjective in asserting that the social world is a constructed reality, but go further to suggest that social power and discourses and restrictive conditions shape this reality (Hesse-Biber & Leavy, 2010). The study described in the above illustrated the complex, negotiated, and iterative processes involved in wheelchair provision (Mortenson & Miller, 2008). The authors critiqued the assertion of client-centered practice, given the discrepancies in power between stakeholders, and suggested the potential benefit of peer resources, particularly for new AT users. Competing goals or environmental barriers in wheelchair provision were highlighted as factors that ultimately lead to compromised AT choices.

In an example from social services, Canadian researchers explored how the ideal of consumer choice was enacted in a vocational re-training program, using discourse analysis from focus groups of consumers and service providers and analysis of policy documents (Maceachen et al., 2013). The findings illustrate tensions between the program ideals and the practical constraints on choice experienced by consumers. Choice was not available for some program aspects that consumers considered important, and administrative structures meant there were time and cost constraints that put pressure on consumers to make choices.

The authors advocated for expert guidance or advocacy for consumers, but cautioned about the use of case managers in this role, because they face competing demands of meeting cost objectives and following restrictive rules not always consistent with the best of interests of consumers (Maceachen et al., 2013). Case managers were required to make choices on behalf of consumers if the initial choices of consumers were not consistent with policy intentions or system capacity. The lack of discretion for consumers making choices increased tension in their relationships with case managers. A limitation of this study design was that the participating consumers and service providers were not involved in the same episodes of care, meaning the findings from this study may also be representative of the diversity of experiences in different service delivery encounters, and cannot point to particular aspects of the consumer-provider interactions that promoted or constrained choice. However the critical analysis in this study has important implications for policy-makers, and also demonstrates the importance of an interpretive approach that seeks feedback from service providers and consumers on their expectations and experiences of choice in practice, to ascertain whether the expectations are shared and ideals realized.

RESEARCH METHOGOLOGIES

Research can be used to test or develop theory, and describe or evaluate practice, depending on the epistemological stance and research aims (Crowe et al., 2011). Theories are tested in positivist research, with the aim of distinguishing between fact and opinion by using rational and logical research methods. Positivist research does not always deliberately manipulate the environment, as in experimental designs, but can test pre-defined independent and dependent variables.

As an example, claims that choice increases equity of access to health services, and improves quality and efficiency were tested in a literature review conducted in 2004-05 (Fotaki et al., 2008). The researchers analysed the aims and outcome of policies introducing choice into healthcare with a sample drawn from the USA, European Union, and United Kingdom that included choice of treatment, General Practitioner (GP), hospital specialist, and

hospital or aged care residence. The reviewers tested policies against their stated and implied effects and then compared them to published evidence for key healthcare outcomes: quality of care, responsiveness, efficiency and equity. Findings from the review highlighted the complex processes and unpredictable outcomes that follow the introduction of choice in health policies. The authors noted that the introduction of choice stimulated quality improvements from service providers, but also increased costs. They commented on the complexity and uncertainty of choices in healthcare when compared to other consumer choices, and the wide variation in consumers' desire for involvement and support with choices. The independent variable of choice policies did not appear to increase efficiency of health care, or decrease inequalities for consumers.

However, if people's actions are influenced by their interpretations or by the context in which they are situated, there are many variables that will contribute to their behaviors. Complex phenomena, such as AT provision, cannot be broken down into independent components and explained by simple causal relationships or hypotheses. Personal and contextual factors influence AT choices, including social norms, such as the value of independence, that pressure people to accept AT to avoid dependence (Hocking, 1999). Processes of assessment, trying to match devices to a user's profile, including their activities and finances, contribute to potential users' perceptions that a device might be an acceptable solution (Lindqvist, Nygard, & Borell, 2013; Ripat & Booth, 2005). The social environment in which this occurs for consumers may provide encouragement and recommendations (Gramstad, Storli, & Hamran, 2013). Consumers have attributed contact with other consumers or healthcare professionals, and awareness of options, to feelings of being informed in AT acquisition (Martin, Martin, Stumbo, & Morrill, 2011).

According to interpretive and critical stances, society does not exist as an objective or observable phenomenon, so people's behaviour cannot be generalised to other people or situations, or even the same people at different points in time (Crowe et al., 2011).

The relational, rather than individual, context of healthcare is highlighted in a study on the role of key professionals in supporting choices made by people with disability (Wilde, 2013). Adults with fluctuating or sudden-onset medical conditions who accessed health or social care services in England (service users), participated in interviews over three years about their experiences of choice. Five of the service users nominated a person who had been closely involved in making choices or managing the consequences of choices, and the five nominated 'key professionals' were interviewed about their role in supporting a choice that had been described by the service user. Narrative analysis was used to compare the accounts of both the key professionals and service users. The findings illustrated service users' desire for continuity of support, and the ways that professionals helped them, over time, to develop their knowledge of options and understanding the services and systems to be negotiated. The relationships influenced the quality of decision-making and management of uncertainty through 'co-production'. The study demonstrates how case studies use multiple sources of evidence to examine why decisions were made, how they were enacted, and with what effects (Exworthy, 2012).

Research into AT provision must take into account the social and political environments in which it is situated. Interpretive stances have been adopted in research into the meaning and exercise of choice for people accessing health and social care services. Contextual factors, such as culture and embedded norms are have been found to be significant in determining the extent to which patients experience choice (Thomson, 2006). Such findings may lead researchers to take a reflective or critical perspective at times when undertaking interpretive research, and it is not uncommon for researchers to adopt more than one approach to extract meaning and use case studies that examine phenomena at both micro and macro levels (Crowe et al., 2011).

As an example, secondary analysis of data allowed researchers to reflect on the nature acquiring and maintaining AT as an ongoing process of decision-making, and part of self-management. The study used focus groups at sites in the USA and Canada and analysed the

perspectives of 45 adult users of mobility AT, 10 of their caregivers, and 10 service providers (Hammel et al., 2013). It aimed to compare and contrast the perspectives and priorities of different stakeholders by asking AT users and their caregivers to describe processes they engage in when acquiring and maintaining AT devices for mobility, such as deciding which devices to use to address specific mobility problems, and when to ask for help. Participants also described how they developed solutions for poor fit with the physical or social environment, or constraints in service delivery systems. The researchers highlighted the correspondence of these processes with core self-management activities such as problem-solving and decision-making. Self-management skills and confidence influenced outcomes including device abandonment, and choice and control in life across participation domains. The study also reinforced the need to evaluate the influence of contextual elements at both micro and macro levels to avoid wrongly attributing outcomes from AT use to the device or individual user (Hammel et al., 2013).

CONCLUSION

Empirical research demonstrates that contextual and relational factors influence stakeholders' choices and experiences of AT provision. Choices are made over time and via interactions between individuals that occur in a social context, and may be enabled or constrained by funding and policies, or their interpretation by providers, resulting in the construction of choices and their boundaries even before a consumer accesses an AT service (Maceachen et al., 2013; Rosenberg & Nygård, 2012). The majority of literature on choice in AT provision has focused on the decision-making of providers or the range of AT devices available in local markets, but consumers and caregivers have also described an ongoing process of decision-making when acquiring and using AT. Providers and consumers vary in their needs and expectations for involvement in choice, influencing the power in their relationship and approach to AT provision (Hammel et al., 2013; Mortenson & Miller, 2008).

The ambiguity of choice as a policy principle and the complexity of AT acquisition must be embraced to understand how choice is conceptualized and realized in AT provision. This requires an interpretive perspective that captures both and micro and macro-level factors, such as funding arrangements that restrict the type and quality of AT devices and services available (Hammel et al., 2013). It should also consider the experiences and perspectives of key stakeholders in AT provision, including consumers, practitioners and policy-makers (Maceachen et al., 2013), and their relationships with each other (Wilde, 2013). Acknowledging the means through which particular discourses of choice come to dominate the policies and practices of AT provision will assist in addressing the important and contemporary challenge of how society can support and include a growing population of people with disability.

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