Reviewer's report

Title: The emotional base of self-care in chronic illness: A qualitative study of the role of health professional support in the self-management of type 2 diabetes.

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Reviewer: Sally Thorne

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This paper describes a study on a topic of considerable importance related to the effectiveness of current methods for health care professional engagement with patients attempting to develop self-care management skills in relation to type 2 diabetes. It presents findings from a subset of a larger study, specifically focus groups to illuminate perspectives of culturally diverse subsets within the local clinical population.

While the topic is highly relevant and the authors are to be applauded for attempting to work within the inherent complexity it entails, this manuscript does not yet do justice to the conceptualization required of an effective qualitative report that would contribute meaningfully to the larger dialogue. I have outlined the major areas of concern that I have, and offered a few thoughts as to how this data base might be reworked to yield a more defensible set of findings.

In the background section, there seems to be some conflation between chronic illness self-management programs and the specific variety that are self-led, one-off, and disconnected from mainstream health. Thus comments about their ineffectiveness seem to interpret evidence from the latter context in an overly general manner. In the countries cited, numerous initiatives exist whereby self-care management reflects a different philosophical approach to health care communications and service delivery systems for this population, rather than a discrete and specific set of patient-run group meetings. It will be important to interpret the existing evidence about effectiveness with these distinctions in mind.

A challenge in the overall logic of this study is that it conflates the descriptive with the normative. In other words, by documenting that patients describe that social support within their particular communities/families is important to them, the study cannot really determine that this is how things “ought” to be done. For example, the study explicitly recruited for those who had poorly controlled disease. Their consistent report that they felt supported by their families becomes quite problematic when redirected into a guideline for future practice. One might hypothesize, for example, that the social support of some families could theoretically be a powerful barrier to the development of effective self care management skills over time. In other instances, that family support might well be the key to eventual effectiveness. Thus without a sense of the outcome measure (with no capacity to interpret the findings of their self reports against a comparable sample of those who had developed effective self care skills) it
becomes very problematic to make explicit recommendations for clinicians. Indeed the complexity of these kinds of issues suggests that simplistic interpretations may be quite contraindicated here.

The research method is not clearly depicted. While focus groups were used as a technique for data gathering and thematic analysis is described as the method for interpreting the group interview transcriptions, the methodological basis for design decisions is not explicitly justified. What conceptualizations or theoretical orientations would have prompted the analysts to see certain groupings of data as “themes” for example, is never explained. Thus, the findings as reported may reflect such things as the topics about which there is a greater volume of data, or around which there was no apparent dissention, rather than those which might be conceptually interesting given what is known about this phenomenon on the basis of prior science. In fact the major groupings that account for the findings seem quite likely to derive directly from what might have been the prompts or trigger questions for the interview, thus verbal expressions in response to questions may not mean that the issues are of particular importance in the larger sense of how illness and self care are experienced.

One of the central problems with focus groups is that they are designed with the explicit aim to draw a group toward a common perspective. Unlike individual interviews, in which one exploits specific cases, the focus group method consciously recognizes that people in groups tend to express that which is normatively appropriate for the group. Thus it is important not to assume that the prominent theme is in fact what would have been expressed by each individual separately. This notion becomes quite important when presenting comparative findings related to ethnocultural populations. For example, in cultures in which it would be bad form to contradict an elder or patriarch, an early pronouncement by a dominant group member can preclude any access to diverse opinion that may in fact exist within the group. Researchers must keep this characteristic of focus groups in mind when reporting and interpreting what they consider to be “findings” so that those claims don’t extend beyond what can be known using the method that was applied.

The analysis becomes confused when it moves into the area of gender influence. Clearly gender emerged as a factor, in that men across the sample seemed more likely than women to have wives cooking for them. However, given the nature of the study, this kind of observation deserves mention as something noticed in the course of the study, but cannot be construed as a “finding.”

In the discussion, it is noted that further work would be required to “test theories generated from this study.” In my view, it would not be appropriate to reference the observations made on the basis of these data as “theories,” but rather to try to conceptualize them in a manner that is consistent with the limits and constraints of the methodological approach. It would appear that the authors may have overly relied on a very basic technique textbook, using a rather mechanical description of thematic analysis out of context of the methodological orientation within which it is normally used. I would strongly recommend grounding any revised version of this work in a more thoughtful and analytic methodological
stance, such that the logic of what was done and what it might mean can be audited by a reading audience. I am not suggesting undoing what has been done, but perhaps going back at the data that exist with an eye to what its nature and characteristics are, and how those will shape what can properly and appropriately be claimed on the basis of an interpretive analysis of it. Some sources that would work even at this late stage are:


In the discussion of findings, it again becomes evident that the researchers were attempting to do too much (answer too many questions) on the basis of limited data and minimal indepth analysis. Certainly all of the issues deserve study: it is important, for example, to better appreciate how typical family structure within Turkish immigrant communities may define or shape conceptualizations of their illness according to recognizable interpretive patterns. However, by oversimplifying the analysis, one comes away with the impression that Turks ought to focus on stress and Caucasians on resentment, and that this observed distinction is both clinically and culturally important. While it may be, I think the reader will require much more convincing through the presentation of a rigorous and careful treatment of findings before that conclusion is warranted as a research product. I therefore suggest that going back into the analysis, and focusing the interpretive report on a particular theme or perspective that can be developed in more depth, moved past the stereotypic and into the thematic pattern analysis, would be helpful.

Because of the methodological (and theoretical) concerns I raise above, I have significant worries about the conclusions as currently reported. In essence, it seems to me that the authors are advocating a status quo position in which family support mechanisms be supported and not inadvertently interrupted. However, there seems no place within which this perspective is being linked to clinical outcomes. To put the point in the extreme for the purpose of illustration,
even if all of the people in the focus groups had advocated a “leave us alone” stance, it must be recognized that were selected because they were not managing well. Thus whether it is or is not a good idea to support these powerful familial webs has not been determined on the basis of the findings of this particular study. That seems to me an especially pressing question, and with a rethink of the data and an alternative angle of analysis and presentation, there might be some clues that this study could offer us toward beginning to answer it.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests