Mental health risk, safety, and the lost soul

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Abstract

Introduction: People's lives depend on mental-health problems being recognised at an early stage so that risks such as suicide and harm to others can be detected and appropriately managed. This was the motivation for the GRiST web-based decision support system. It was developed to bring mental-health expertise into the community so that people can detect risks even if they do not have specialist mental-health training themselves.

Methods: The research started in 2002 using a mixture of methods, including interviews, thematic analysis represented by mind maps, focus groups, and action research, all realised within the evolving GRiST software.

Results: The GRiST web version was adopted in earnest from 2010. It has now accumulated nearly one million risk assessments from practitioners in specialist mental-health services. The latest research has reached out to people in the community by providing a new self-assessment version, myGRaCE. People can use myGRaCE to help understand their own mental health problems, find out where the main issues and risks reside, and create a comprehensive report that helps them receive appropriate support.

Conclusions: The paper describes the development of GRiST and how it has tried to shift the focus from organisations to the individual. Pressure to constrain risk evaluation to include only risk-specific symptoms has been resisted because the prevailing context and long-term causes are all fundamental to detecting and managing risks. The whole person has to be understood: body and soul.

Keywords: decision support, GRiST, mental health, myGRaCE, risk assessment

Introduction

Mental health is rising up the political agenda and its importance is confirmed by statistics: 16.2% of adults in England have at least one common mental-health disorder (The Information Centre for Health and Social Care, 2009). These disorders increase the risk of suicide 11-fold (Harris and Barraclough, 1997) and contribute to suicidal behaviour being a leading cause of injury and death across the globe (Nock et al., 2008). And yet mental health remains underfunded, often being the service that has a chunk taken out of it when austerity bites, which looks like being an omnipresent threat unless wealth is generated and distributed more fairly.

The problem is that mental health is rooted in complex causes that require strategic planning and a change in societal values. The best way to reduce the load on mental-health services is to address these causes but it is a long-term solution that politicians not only fail to address but don't agree on in the first place. Instead, when government funding is tight, mental health services are the first to be squeezed because the need for treatment and saving lives is more obvious in acute services. In short, mental health problems are

chronic, hard to see, difficult to treat and not easily directly connected to outcomes. Bad press and government opprobrium are more likely to come from problems with acute care and governments spend money where they think it will improve their image.

This is the backdrop for the research programme described in this paper. It reports on how the Galatean Risk and Safety Tool, (GRiST, 2016), was developed and implemented in mental health services that are struggling with both information technology and understaffing. GRiST was designed to help detect and manage risks associated with mental-health problems, including suicide, self harm, harm to others, self neglect, and vulnerability. The goal was to bring practitioners and service users closer together, with service users being equal partners in collaborative care.

The theme running through the research is how risk and safety issues cannot be understood and managed without looking at the contexts of people's life histories and current social circumstances. This was not always how clinical services saw it, though; time pressures and limited resources meant they initially wanted to limit assessments to risk-specific symptoms only, such as previous risk episodes and current intention.

The reduction of people to specific risk behaviours in isolation from a holistic view of their mental, physical, social, and historic life impacts on the accuracy of risk evaluations as well as decision making for addressing risks. A person's soul or spirit is fundamental to their mental health and people cannot be understood without it. This paper will describe how GRiST keeps hold of the soul and connects people to mental-health expertise. The motivation and objectives of the research is followed by the methods used for developing GRiST over a fifteen year period. Results from implementing GRiST in practice show how it meets the needs of different types of people and assessment contexts. The discussion will review how well the holistic person has been retained and the paper will conclude with the next steps for GRiST.

Objectives

The precursor to GRiST was funded by a mental health Trust in England with the aim of producing a rapid screening tool for assessing multiple risks. It was organisationally motivated in that their current tool was deemed too long and unwieldy: time and resources were the drivers.

Interviews with mental-health practitioners were conducted to determine the most important factors for evaluating risks. It soon became clear that the number of items identified would make the tool much longer than the commissioners wanted. This was an early warning of the paradox that GRiST has faced throughout its development and implementation: evaluating and managing mental-health risks is a complex process that requires good quality information that nobody has time to collect.

The pilot outcome led to a much larger grant from the Department of Health in England for developing a web-based decision support system (DSS), GRiST. The objectives stated in that proposal were ambitious and are given here in some detail:

A decision support system for mental-health risk assessments that will be a constantly--evolving, evidence-based, world-wide web site for mental-health risk assessment. It will contain resources of three types:

1. a database of client cues and associated risk judgements provided by practitioners as part of their clinical practice;
2. a suite of statistical and pattern recognition tools for analysing the database and elucidating the association of cues and risk;
3. a validated psychological model of risk assessment based on multi-disciplinary clinical expertise; it will provide a full analysis of how clinicians perceive the contribution cues make to different forms of mental-health risk.

Specific components of the DSS include:

The Galatean Risk Screening Tool, GRiST, for collecting client risk data

The tool identifies the information relevant to risk assessments and provides the means for recording it, both in a downloadable (paper) format and directly through the web browser. The information can then be used to generate statistical or expert-based risk assessments.

The galatean model of mental-health risk assessment

Risk categories are represented by hierarchical knowledge structures called galateas (Buckingham, 2002), elicited from a multi-disciplinary group of expert mental-health clinicians. They have facilities for tracing and explaining the generation of risk from client cues, through a hierarchy of concepts underlying risks, to the high-level risks themselves. The explanations will be intuitive, resonate with the clinician's own understanding of risk, and be fully comprehensible, partly because galateas are based on a psychological model of classification.

A database of anonymous client information

Data from the application of GRiST in clinical practice will be stored in a database and contribute to the general evidence base for mental-health risk, as well as being available for analysis within the DSS itself.

General clinical outcomes associated with the DSS are expected to be: better identification of people at risk; a reduction of inappropriate referrals; earlier risk detection; knowledge about risk-assessment expertise; knowledge about mental-health risk; support for education and training of mental-health practitioners; better interdisciplinary communication of risk; increased consumer awareness of mental-health risk and appropriate interventions; and improved clinical governance.

These were extremely ambitious objectives that are hard to measure let alone deliver. This paper will describe the main methods and provide the latest results.

Methods

Mixed methods were used, including qualitative interviews, thematic analysis, focus groups, and action research. The software development was designed to produce versions of GRiST that evolved over a sequence of iterations. The flexible delivery of end-user functionality was built into the underlying knowledge base, which integrated clinical expertise with organisational requirements. These could easily be changed in the knowledge without having to update the end-user software.

Interviews and thematic analysis

The initial method was to conduct interviews with 46 multidisciplinary mental-health practitioners (Buckingham et al., 2008). The initial question was open ended, simply asking the practitioner to imagine they were in their normal environment and assessing a service user for mental-health problems and associated risks. What are the most important factors that need to be explored? The interviews were audiotaped and transcribed before each one was made into a mind map (Buzan, 2003) using the open-source Freemind software (Freemind, 2014).

These mind maps were then combined into a single consensual model (Figure 1 shows a small portion of it) and converted into a hierarchical knowledge structure of the risk expertise (Buckingham et al., 2007). This knowledge structure was based on how mental-health practitioners think and reason about mental health risks. It identified the concepts and underlying data that need to be collected, in a format that was close to the experts' own representations. This is the strength of cognitive modelling (Farrell and Lewandowsky, 2011) for building decision support systems: it brings the computer and human closer together, with less need for translation and more intuitive interactions.

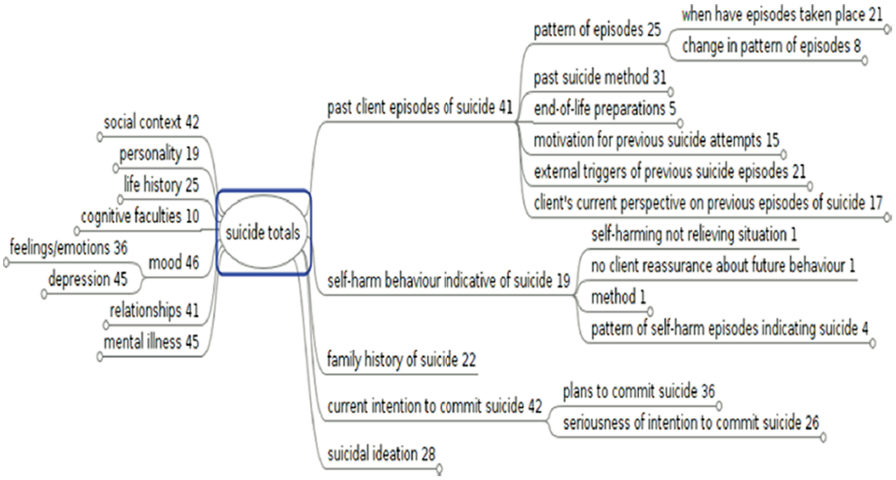

Fig. 1 Part of the mind map for suicide risk resulting from analysing the practitioner interviews

The number on each branch is for the total number of interviews that mentioned that particular node or any of the nodes within it. Nodes with a little circle on the end indicate that there are branches within it that have not been expanded.

Focus groups and action research

The original knowledge structure was for working-age adults only. It was refined through focus groups and as part of discussions with service providers prior to its implementation within their organisations. Pilots were set up within the GRiST website, which meant organisations could trial the system without having to link it to their own information technology. The pilots were able to demonstrate the core functionality to end users while the GRiST team negotiated with the managers over a full implementation. The key to success

was flexibility: make the route to implementation as easy as possible and ensure GRiST meshes with the existing information flow and practices.

Results

The first secondary-care mental-health trust to use GRiST started in 2010 with just the working age adult version. Since then, more trusts have adopted it and new versions of GRiST have become available, including ones for older adults, children and young people, learning disabilities, forensic services, primary care, carers without any clinical training, and service users for self-assessments.

Tab. 1 The actual risk judgements given by assessors and the mathematical predictions generated by GRiST

Actual Risk	Predicted Risk										
	0	1	2	3	4	5	6	7	8	9	10
0	7566	4891	957	161	37	10	5	0	0	0	0
1	4328	8362	3538	807	196	55	18	9	0	0	0
2	1186	4669	5695	2713	780	229	66	14	4	2	0
3	198	1248	2904	3543	1929	630	150	34	11	4	1
4	30	198	603	1266	1670	961	362	97	23	3	1
5	8	73	223	544	993	1067	694	246	72	12	3
6	3	7	39	90	265	414	516	334	102	27	1
7	3	9	14	59	93	201	338	483	340	75	10
8	2	2	4	18	28	71	139	206	325	219	36
9	0	0	1	4	5	11	21	48	81	110	72
10	1	0	1	1	2	0	5	4	11	31	43

On March 11th, 2016, the database contained a combined total of 968,593 completed assessments across all the risks. The totals for each risk were: suicide, 177,853; self harm, 165,074; harm to others, 164,324; risk to dependents, 142,589; self neglect, 147,375; and vulnerability, 171,377. The clinical risk judgements themselves can go from zero (none) to ten (maximum). The distribution is skewed towards the lower end, with frequencies of assessments for each risk level being: zero, 144,161; one, 85,301; two, 71,712; three, 53,436; four, 35,884; five, 31,360; six, 16,473; seven, 14,686; eight, 11,671; nine, 4,535; and ten, 3,024. Either assessors are reluctant to give maximum risk or, thankfully, they are very rare.

The system is used 24 hours a day, every day of the week by nearly 3,000 clinicians, with about 3,000 logins a week. The total number of service users assessed so far is 99,241. Of these, the maximum number of assessments for one person is 143 but the average number is 2.21.

When we started the project, many practitioners were skeptical that they make consistent risk judgements or that their judgements would agree with their colleagues. The challenge for GRiST was considerable because it asked for judgements along an eleven-point scale (0 to 10), whereas many tools limited the levels to low, medium, or high. It turns out that GRiST can actually predict the suicide risk judgement given by an assessor within plus or minus one of the assessor's judgement for more than 80% of the assessments (Saleh,

Buckingham, 2014). The confusion matrix in Table 1 shows how the actual and predicted judgements correlate much better than the practitioners thought. The figures combine clinical disciplines from different organisations but still confirm the consistency and expertise of the practitioners.

The general risk knowledge structure and coverage

Figure 1 shows part of the collective knowledge obtained from the original mental-health experts interviewed for GRiST. The numbers against each branch are the total number of experts who mentioned the topic in their interview or some sub-branch of it. It is clear from the map that both suicide-specific factors such as history and current intention are important as one would expect, but so also are generic factors such as a person's social context (living arrangements and any detrimental changes in particular), mood, relationships and their general life history. This is because evaluating risks goes hand-in-hand with managing them, with the former addressing predominantly the symptoms, which tend to be more risk-specific, and the latter considering the underlying causes, which will be rooted in the holistic person.

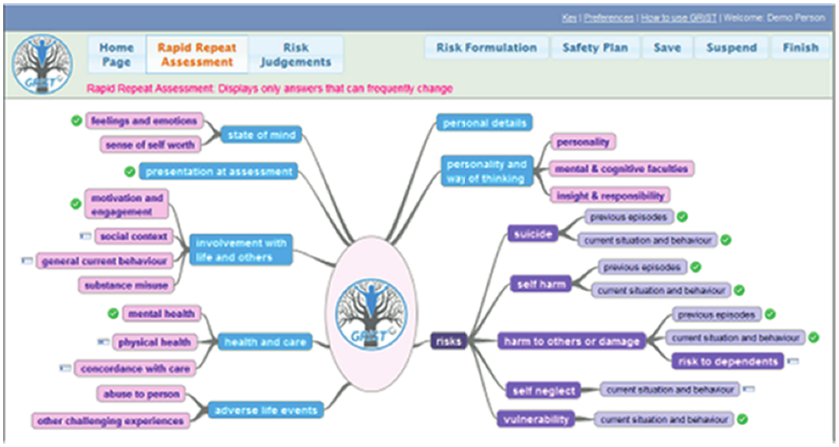

Fig. 2 The mind-map screen for the dynamic version of GRiST

Each branch of the mind map can be selected and it takes you to the screen showing only questions associated with that branch. The particular mode is for rapid-repeat assessments so the small "progress bars" show those branches with rapid-repeat questions that frequently change their values. Ticks next to branches mean all the questions have been answered for those branches.

Even risk judgements (as opposed to management) are not entirely reliant on risk-specific data. Our mathematical analyses (Saleh and Buckingham, 2014) demonstrate the important influence that hopelessness, impulsivity, feelings and emotions, and current mental illness have on clinical risk evaluations. If risk tools split such generic information from the risk data, there is a danger that risks may not be correctly calibrated as well as being disconnected from the information needed to manage them. The folly of such separation was confirmed by an exploratory study of risk management in a secondary care Trust (Gilbert et

al., 2011). It is why GRiST keeps everything together, as shown by the mind map overview of GRiST knowledge that provides access to questions in the web-based system (Figure 2).

Different interfaces and collaborative care

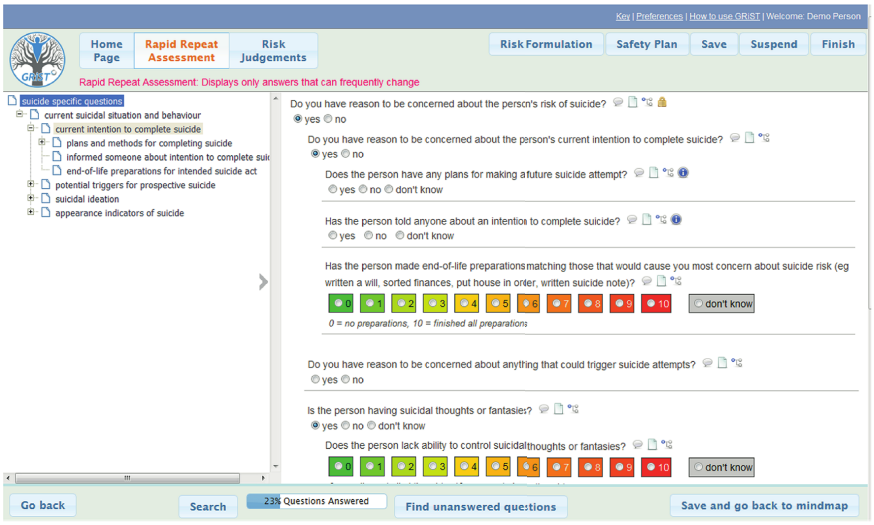

Fig. 3 Data-collection screen for the dynamic GRiST version

The questions are in the right-hand panel and the selected branch of the mind map is the knowledge "subtree" in the left-hand panel. Any part of the left-hand panel tree can be selected and then only those questions associated with it will show in the right-hand panel.

Mental health and risk assessments in particular are sensitive issues, with stigma and vulnerability at their heart. Common complaints of service users are that their independence and autonomy are compromised. Things are done "to" them rather than "with" them. This has begun to change more recently. The UK Health Foundation has campaigned for "co-creation" of health where the service users and providers work together in an equal partnership. Shared decision making is a related policy that has equally gained credence. The upshot is that people should actively participate in and have responsibility for their health care, alongside the health professionals. For GRiST, this meant using the decision support system during the assessment to support the process rather than simply record it. The original practitioner interface was designed for the latter: rapid and efficient data entry after the event. The more recent interfaces show how selecting any part of the mind map (Figure 2) can take you directly to the related questions in the resulting data-collection interface (Figure 3). Together, these interfaces make it very easy to find the relevant questions in real time, without interfering with the natural flow of assessments. Both interfaces can be tried out at the GRiST website, www.egrist.org.

Self assessments

The final transfer of control to service users is to give them independent and autonomous access to the GRiST decision support system. A self-assessment version of GRiST was

developed in parallel with the practitioner version (Buckingham et al., 2015). It is a direct consequence of our central theme that problems are embedded in people's holistic life circumstances and histories and it is the people themselves who know the most about them. The self-assessment version of GRiST was designed to tap into their expertise and ally it with the embedded expertise of all the practitioners who have helped develop GRiST.

The resulting system was called GRaCE: the Galatean Risk and Care Environment that now encompasses the wider remit of integrating service user and practitioner expertise to produce well grounded and clearly understood plans for reducing risks and improving mental health and wellbeing. Self assessments using myGRaCE can be linked to practitioner assessments within the web-based system to help monitor and support people remotely in the community. This accords with the changing priorities of mental health care, which is to support people at home rather than within institutions.

Discussion

This journey from a practitioner centric view of mental health risk and safety management to a shared activity between equals is about prioritising the person rather than organisational processes. GRiST has shifted from the original data-collection role to a fully-fledged decision support system. The collective wisdom embedded in the GRiST database through its associations of patient data and clinical risk judgements is now being used to provide evidence-based advice for both individual practitioners and service users.

People's lives depend on mental-health problems being recognised at an early stage so that risks can be detected and appropriately managed. The continuing stigma attached to mental health problems and the underfunding of services obstruct early recognition. The steadily decreasing suicide rate in the UK since the late 1980s has stopped since about 2008 and, in England, has begun to rise again (Office of National Statistics, 2016). More needs to be done and particularly with better access to support services.

GRiST was developed to address access by bringing mental-health expertise into the community so that people can detect risks even if they do not have specialist mental-health training themselves. Social services, housing associations, emergency services, and primary care practitioners would all benefit, with some now using GRiST.

However, embedding information technology into organisations is a difficult process because of the politics and change-management issues to be addressed. The self-assessment version of GRiST, myGRaCE, circumvents the process. Rather than going through organisations to reach people, myGRaCE gives people direct access. They can use myGRaCE to help understand their own mental health problems, find out where the main issues and risks reside, and create a comprehensive report that explains their situation to the appropriate clinical services. The service user is spared providing a repeated and painful narrative of their lives that is difficult to express under the best of circumstances, let alone when the practitioner is aware of an impatient queue outside the consulting room. Instead, the practitioner can focus on the areas of most importance but without losing the full context, which is fully explained in the report.

Conclusion

The GRaCE research is now working on helping support older adults so that they can live safely in the community rather than in managed residential care. The idea behind this GRaCE-AGE project is to deploy a variety of sensors in the home to pick up information related to risks and safety management, which can then be automatically entered into GRaCE. This would reduce the burden of data input required by the older adults themselves but also provide a mechanism for monitoring their safety on a continuous basis. If GRaCE detects problems, the care network of family, friends, carers, or mental-health practitioners can be alerted appropriately, but where the older adults are in complete control of how and who is alerted.

Information is the key to better risk management and if this information can be collected and used to support people in the community, this is beneficial to all concerned. People do not have to be wrenched from their social and physical roots and organisations can release residential services for those who most need it. GRaCE is an important resource for collecting this information efficiently, comprehensively, and ecologically, within people's natural environment, which includes their soul, not risk solely.

Ethical aspects and conflicts of interest

Separate ethics approval was obtained for the development of GRiST and myGRaCE, and for data analysis of the anonymous risk database. The authors are all members of the team developing the software.

References

BUCKINGHAM, C. D., 2002. *Psychological cue use and implications for a clinical decision support system. Medical Informatics and the Internet in Medicine*. **27**(4), 237–251.

BUCKINGHAM, C. D., AHMED, A. a ADAMS, A. E., 2007. Using XML and XSLT for flexible elicitation of mental-health risk knowledge. *Medical Informatics and the Internet in Medicine.* 32(1), 65–81.

BUCKINGHAM, C. D., ADAMS, A., E. a MACE, C., 2008. Cues and knowledge structures used by mental-health professionals when making risk assessments. *Journal of Mental Health*. **17**(3), 299–314.

BUCKINGHAM, C. D., AHMED, A. a ADAMS, A., 2013. Designing multiple user perspectives and functionality for clinical decision support systems. In: GANZHA, M., MACIASZEK, L. a PAPRZYCKI, M., eds. *Proceedings of the 2013 Federated Conference on Computer Science and Information Systems.* s. 211–218. ISBN 978-1-4673-4471-5.

BUCKINGHAM, C. D., ADAMS, A., VAIL, L., KUMAR, A., AHMED, A., WHELAN, A. a KARASOULI, E., 2015. Integrating service user and practitioner expertise within a web-based system for collaborative mental-health risk and safety management. *Patient Education and Counseling.* **98**(10), 1189–1196.

BUZAN, T., 2003. *The mind map book.* London: BBC Consumer Publishing. ISBN 978-1406647167.

FARRELL, S. a LEWANDOWSKY, S., 2011. *Computational modeling in cognition:* Principles and practice. London: Sage. ISBN 978-1-4129-7076-1.

FreeMind [online]. 2014. [cit. 2014-04-01].
Dostupné z: http://freemind.sourceforge.net/wiki/index.php/Main_Page

GILBERT, E., ADAMS, A. a BUCKINGHAM, C. D., 2011. Examining the relationship between risk assessment and risk management in mental health. *Journal of Psychiatric and Mental Health Nursing.* **18**(10), 862–868.

GRiST: *Galatean Risk and Safety Tool* [online]. 2016 [cit. 2016-03-11]. Dostupné z: www.egrist.org

HARRIS, E. C. a BARRACLOUGH, B., 1997. Suicide as an outcome for mental disorder. a meta analysis. *British Journal of Psychiatry.* **170**, 205–228.

NOCK, M. K., BORGES, G., BROMET, E. J., CHA, C. B., KESSLER, R. C. a LEE, S., 2008. Suicide and suicidal behavior. *Epidemiologic reviews*. **30**(1), 133–154.

OFFICE FOR NATIONAL STATISTICS. *Suicides in the United Kingdom: 2014 registrations* [online]. 2016. [cit. 2016-03-12]. Dostupné z: www.ons.gov.uk/peoplepopulationandcommunity

SALEH, S. N. a BUCKINGHAM, C. D., 2014. Handling varying amounts of missing data when classifying mental-health risk levels. *Studies in Health Technology and Informatics.* 207, 92–101.

THE INFORMATION CENTRE FOR HEALTH AND SOCIAL CARE. *Adult psychiatric morbidity in England, 2007: Results of a household survey* [online]. 2009. [cit. 2016-03-12]. Dostupné z: http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng

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